NARRATIVE BASED MEDICINE:
A REVOLUTION IN CLINICAL CARE

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ABSTRACT

Background: The field of narrative-based medicine (NBM) emerged as a topic of academic study at Columbia University in 2001, started by Dr. Rita Charon. Developed to be the polar opposite to the existing model of evidence-based medicine (EBM) which focuses on quantifiable data, NBM works to prioritize individualism in clinical settings through narration as well as active and attentive listening. Narrative-based patient care offers clinicians a way of better understanding how individuals process their illness(es) and allows both patient and doctor a means of cultivating a cooperative relationship built on empathy and trust, especially necessary in cases of chronic illness.

Objective: The aim of this study is to evaluate the efficiency of narrative-based medicine and ways to integrate it into the current systems of patient care.

Design and Methods: This assignment is based on existing and contemporary literature regarding the understanding of narrative-based medicine in relation to evidence-based medicine, the benefits and challenges faced by NBM, and ways of blending the two approaches to cultivate an optimized approach to both patient care and the doctor-patient relationship.

Results: The significance of this study is that the existing model of evidence-based medicine lacks the level of individualism and empathy needed by patients to encourage complicity in care, and providers in understanding how singular experiences impact one's journey through and with illness. The inclusion of narrative-based medicine into the system of evidence-based medicine stands to increase the quality of care that patients receive.

Conclusions: There is a considerable necessity for NBM for patients, especially those with chronic illnesses. The desire for integration between NBM and EBM is ongoing, culminating, hopefully, in a better understanding of patients' and doctors' needs in order to give/receive the best care possible.

Keywords: Narrative-based medicine, Evidence-based medicine, storytelling, narration, medicine, chronic illness

CHAPTER 1

INTRODUCTION

Background and Overview

Narratives have been used in medicine for thousands of years. More recently, this time-consuming practice has taken a back seat to evidence-based medicine with its reliance on physiological testing. More recently, narrative-based medicine (NBM) has seen renewed interest as it has been recognized to extend the treatment of illness beyond an analysis of physical evidence. NBM explores the idea that, instead of just looking at clinical evidence, doctors should also listen to their patients when they tell them what's going on with their bodies. It recognizes that the patient's voice is a critical piece in diagnosing and treating illness.

The Master of Science in Narrative Medicine at Columbia University was founded in 2001 by Dr. Rita Charon (Columbia University, 2022). This program "prepares health professionals, writers, and scholars to apply the skills and values of narrative understanding to improve outcomes for both patients and caregivers, and to investigate issues pertinent to health and healthcare in a rigorous transdisciplinary setting" (Columbia University, 2022). This was a revolutionary idea at the time. NBM takes evidence-based medicine, or EBM, and adds a form of humanity to it, making it so the patients are seen more as people rather than numbers.

Doctors diagnose mainly through EBM, by reviewing clinical data. This may include physical manifestations (a rash, a lump) or measured data (body temperature, heart rate, blood pressure, blood analysis). Once a diagnosis is made, the physician will typically treat the symptoms. So perhaps a medication is prescribed to lower blood pressure or treat a rash. NBM, however, uses a form of listening, attentiveness, and narration to get to the root of the problem, i.e. what causes the symptoms in the first place and make sure that the body is fixed instead of merely repaired. It also allows the clinician to understand how the illness is affecting the patient's life.

Research Questions

This study will address the following research questions:

RQ#1: *How does a narrative approach compare to an evidence-based approach to clinical care?*

RQ#2: *What are the positive and negative aspects of narrative-based medicine?*

RQ#3: *How can narrative-based medicine be integrated into the existing model of evidence-based medicine?*

CHAPTER 2

INTRODUCTION

Narrative-based medicine, or NBM, extends the treatment of illness beyond the analysis of physical evidence. Formalized in 2001 by Dr. Rita Charon at Columbia University, it explores the idea that, instead of just looking at the evidence, doctors and other clinicians should also listen to their patients when they tell them what's going on with their bodies. It recognizes that the patient's voice is critical in diagnosing and treating illness. It's a revolutionary idea. NBM takes evidence-based medicine, or EBM, and adds a form of humanity to it, making it, so the patients are seen more as people rather than numbers. Doctors are taught to diagnose mainly through EBM, by objectively reviewing clinical data. This clinical data may include physical manifestations (a rash, a lump) or measured data (body temperature, heart rate, blood pressure, blood analysis). Once determining a diagnosis, the physician will typically treat the symptoms. So perhaps a medication is prescribed to lower blood pressure or treat a rash. NBM uses a form of listening, attentiveness, and narration to get to the root of the problem, i.e., what causes the symptoms in the first place, and make sure that the body is fixed instead of merely repaired. In this paper, questions of the positive and negative aspects of NBM, how a narrative approach compares to an evidence-based approach to clinical care, and how narrative-based medicine be integrated into the existing model of evidence-based medicine will be evaluated.

LITERATURE REVIEW

When looking at narrative-based medicine (NBM) and the ways it can be helpful in the diagnosis, treatment, and maintenance of illnesses, one must understand the model used for comparison. This understanding is needed because, to fully grasp how NBM's integration stands to benefit the existing system of evidence-based medicine (EBM), one must first understand

what that current model is and where gaps in care exist. Evidence-based medicine applies quantifiable data and *only* measurable data to diagnose and treat illnesses. It uses tools such as randomized controlled trials (RCTs) (Misak, 2009), lab tests, and screens as evidentiary diagnostic and clinical tools. Compared to narrative-based medicine, EBM favors numbers and figures over personal judgment and a patient's individual experience with illness (Charon & Wyer, 2008). NBM also addresses the problem of a paternalistic approach in doctor-patient relationships (Bakht, 2017), where a doctor's value as the expert who knows best supersedes that of the patient in what is best for them. Addressing this power imbalance through narrative-based medicine makes it a favorable model for patients.

Despite the differentiation made between NBM and EBM, there is considerable overlap. One way that narration has contributed to one's clinical understanding is in the way our doctors talk amongst themselves as well as patients. They tote this idea of biomedicine, explaining the ins and outs of one's body, which in itself is a narrative—albeit a special kind of narrative— but a narrative nonetheless (Launer, 2003). While EBM prefers the methodology of randomized controlled trials, narrative-based medicine does not solely rely on evidence found to work for some, or most, but not all, patients. EBM shifts the focus away from one that reflects on individual patients and towards one in which populations with patients that experienced unfavorable results are outliers (Misak, 2009). Doing so means that if a pocket of participants in an RCT has unhappy results, the results of the trial is still favorable for use because the more prominent sect of the population studied had positive results, which in EBM means that the majority of the people at large will have those same satisfactory results (Misak, 2009).

Narrative-based medicine, while successful in many ways, still is not without flaws or faults. However, some of the present benefits are that it is intrinsically therapeutic for the patient

to have control of their narrative and be listened to, prevents a disconnect in understanding that could otherwise be present between patient and doctor, it promotes empathy and improves rapport while strengthening the relationship between practitioner and patient, and enhances the doctor's powers of reflection by increasing awareness to both the patient's narrative and one's reaction to it (Zaharias, 2018).

The therapeutic nature of patients telling their story allows for expression of existential qualities like inner hurt, hope, despair, and grief that accompany a person's illness (Greenhalgh, 1999). By allowing a patient a place to express those existential aspects, one can feel a sense of catharsis in having the present and physical nature of illness addressed and the feelings that go along with it. Cepeda et al., (2008) investigated the effect of incorporating a structured narrative approach on perceived pain and sense of well-being in patients with advanced cancer. In this study, 234 adult patients with cancer reporting moderate to severe pain were observed and asked to write about how the illness has affected their lives. This was a randomized, single blind controlled study taking place over 8 weeks. Patients were assigned to one of three groups: a narrative based group, a questionnaire group, and a control group. The first group of subjects who were asked to write at home, for at least 20 minutes once a week for three weeks, a story about how cancer affected their lives. Group two was comprised of participants asked to complete a pain questionnaire while at home. Finally, the control group was simply asked to attend weekly follow-up visits. Additional questionnaires were given to all participants and used to evaluate pain and sense of well-being. At 8 weeks, no difference in pain rating or general sense of well-being was observed between groups. Despite no intergroup difference, five patients with a high degree of emotional disclosure reported a greater sense of well-being. This outcome stands to show that the act of emotional vulnerability serves as a way of making one more

attuned with themselves; what they still have to be able to feel positive about in their lives, and what they can control in the face of the uncontrollable illness they suffer from (Cepeda et al., 2008). The small number of participants who experienced a greater sense of wellbeing could be in part because of a lack of person-to-person interaction and inability to share their experience with another human. Further studies on narrative approaches could expand on research like Cepeda et al. (2008) by including in person sharing and observation over a longer period of time. Not only does NBM allow for emotional catharsis, but there is evidence showing that narrative-based therapies increase feelings of positivity and decrease feelings of depression, anger, and lowliness among cancer patients (Wise et al., 2018).

In addition, the potential for a disconnect is avoided because of a clear understanding between patient and doctor of the course of action from diagnosis and beyond through attentive listening on the doctor's part to any questions or concerns the patient may have regarding their illness. Careful listening, in turn, promotes empathy and improves rapport because the patient feels heard, and the doctor completely understands what the individual needs and desired outcomes are for whom they are treating. Lastly, enhancement of reflection is beneficial in that it allows the practitioner to recognize and address their predispositions or biases towards a particular approach that the patient is averse to, or a deeper level of understanding of how an individual's experience with illness shapes the way they wish the condition be treated.

Some challenges to narrative-based medicine include potential increased time with the patient during visits and lack of prior training as a reason for not practicing narrative-based medicine (Bakht, 2017). This lack of prior training was observed by Greenhalgh et al., (2005) in a study done to develop bilingual health advocate-led storytelling groups for patients with uncontrolled diabetes in under-served areas of South Asia and to evaluate its impact on blood

glucose levels over time. The researchers faced challenges in training health advocates to provide diabetes education as well as storytelling techniques. Health advocates had difficulties in leading the discussions and the conversations were often chaotic. There, sadly, was not a lot of support from the health center administrators and so the program was on very unsteady legs. No changes in blood glucose levels were observed over time (Greenhalgh et al., 2005). This unfortunate lack of results is not as much a shortcoming of NBM itself, but rather the challenge of integration with assistance from administrators to ensure a smooth transition. It is obvious that in order to guarantee success in training, administration needs to be on the side of being open to new methods. While the argument exists that a doctor would spend more time with a patient, Dr. Vera Kalitzkus (2009) noted that a study showed that 80% of patients needed only two minutes to tell their story in recounting one's medical history. Furthermore, out of 335 patients, only 7 required more than 5 minutes (Kalitzkus, 2009). Finally, the study Kalitzkus cites was done with patients who had long and complicated medical histories, thereby addressing and discounting the counterargument that those with intensive medical pasts would require more time than those who do not (Kalitzkus, 2009). While the study's sample size may be the only objectionable aspect of its design, the results do tell a story that communicates that, in general, a doctor would not need more time to listen to patient narratives. To address the lack of prior training in narrative-based medicine, Bakht (2017) offers an alternative that would require medical professionals to be trained in skills needed by narrative-based medicine: attentive listening, reflective writing, and close reading. While that would not address the issue of existing doctors not being trained in NBM, it would offer a path forward in clinical care where individual narratives are deemed as necessary to patient care as evidence. As doctors who are not previously trained in medical humanities either retire or adapt to changes in

medicine as has historically been the approach, even those without medical school training in NBM can become knowledgeable in appropriately using it in clinical settings.

An article by Nabutaro Ban (2003) states that "competency for the best care of patients with chronic illness is an amalgamation of evidence-based medicine (EBM) and NBM, based upon an underlying infrastructure of behavioral science" (p. 74). While entirely necessary in knowing how to treat a chronic or any type of illness, EBM is not enough alone, especially when treating those with chronic diseases. This is because those with chronic conditions have a more intimate relationship with their physician. It is necessary for the physician to know about what goes on in their lives, including but not limited to emotional changes, behavioral changes, and relationship changes, to best, ascertain the underlying cause of what is going on in the body. This is where NBM and understanding the behavioral sciences come in. The use of these two practices together is more helpful in bringing about a complete picture of what is going on and why.

Because of the difficulty in separating narrative from evidentiary based science, Greenhalgh (1999) argues that narrative-based medicine should not be discredited as something that exists outside and separate from evidence-based medicine, but rather can coexist with it, and allow for patients and practitioners to use both clinical skills derived from evidence-based methods such as lab tests, pathology, symptoms, and make a judgment off of that information, which is in and of itself a kind of narrative.

In addition to these ways EBM would benefit from NBM, some gaps are created by using only EBM that NBM can fix. According to Cheryl Misak (2009), "**…**EBM shifts focus of clinical practice away from reflection on individual patients and towards populations with

unhappy results for patients who are outliers" (Misak, 2009, p. 393). Some competing clinical options are contradictory or incomplete, making the risk-benefit analysis of treatment a gray area if looking just at data to make a clinical determination (Misak, 2009). A remedy for this is using individual judgment to determine what is best for a particular patient and understanding that the efficacy of a treatment for one population may not be the same for another (Misak, 2009).

Another gap is that current medical students are not guided to make subjective clinical judgments and are instead taught to rely on the protocols that EBM offers (Misak, 2009). By integrating narrative-based techniques alongside EBM in medical training enabling medical students to understand that their clinical opinions can, in some cases, offer insight into treatment that isn't expressed in quantifiable data, this inconsistency could be resolved (Misak, 2009).

Narratives are more than chronological accounts of events—narrative gives body and shape to events by imbuing those events with interpretation, motivation, and other gaps in what is thought to be objective (Misak, 2009). Narrative is unavoidable in evidence-based medicine because although much of the EBM patient-provider experience is qualitative (lab tests, scans, exams), they still listen to the patient explain their presenting problem as well as medical history (Misak, 2009). Therefore, because those recountings are narrative-based, it is subject to forgetfulness and motivation for inclusion or exclusion of details. Doctors must then question and interpret the presented narrative to get the most accurate picture of what happened (Misak, 2009). It is important to note that evidence for a particular patient is gathered by listening to their story.

Finally, the clinical method is an interpretive act that draws on narrative skills to incorporate the overlapping stories told by patients, clinicians, and test results. The ability to select the most appropriate medical maxim for a particular clinical decision is primarily acquired

through the accumulation of expertise on the case by ways of the stories or “illness scripts” of the patients as well as clinical anecdotes. Accepting narrative in the illness experience as well as subjectivity in clinical methodology is not dependent on a rejection of principles found in evidence-based medicine.

In conclusion, narration is essential to modern medicine. The combined narrative-based medicine and evidence-based medicine process produce the best results for patients, especially those with chronic illnesses. While some doctors will have difficulty accepting this, it is in there and their patient's best interests for them to learn how to listen attentively and interpret a patient’s narrative, combine it with their narrative, and use it to help create a narrative for treatment that the patient can easily understand. When looking at the benefits and challenges of narrative-based medicine, the need for NBM to address concerns brought up by EBM greatly outweighs its potential shortcomings. Because of the ability for NBM to mollify patients’ anxieties by including them in the process of creating their illness script and help doctors develop an enhanced understanding of the individualist nature of the illness as it presents, NBM stands to be an invaluable tool for patients and practitioners.

CHAPTER 3

METHODS

This study is based on literature going back to 1999 on narrative-based medicine (NBM) and is qualitative and descriptive in its design. I examined relevant, specific, and pointed literature from the origins of narrative-based medicine up until 2018. The purpose of my study on NBM is to understand three areas of focus: what the pros and cons are of NBM, how to integrate it into evidence-based medicinal (EBM) practices, and how it compares to evidence-based medicine (EBM). This study is based on a long-spanning topic, ranging over 20 years at the time of this writing. This research is based on scholarly journal articles, educational debates, and commentaries. Most of the research was acquired through the Purchase College Library Database, specifically ProQuest and EBSCOhost.

I used the following questions to guide my research:

RQ#1: *How does narrative-based medicine compare to evidence-based medicine?*

RQ#2: *What are the pros and cons of narrative-based medicine?*

RQ#3: *How can narrative-based medicine be integrated with evidence-based medicine?*

I used specific terms to gather information from academic articles and online search engines. The search key words included but were not limited to: *narrative-based medicine, Rita Charon, narrative-based medicine and evidence-based medicine, narrative-based medicine and chronic illness, storytelling and health, and narrative-based medicine origins.* I combined them into a digital folder on a google drive specific to my research as well as printing physical copies and organizing them based on the following:

- What is narrative-based medicine?
- How can narrative-based medicine be used in clinical settings?
- How does narrative-based medicine compare to the existing medical model (evidence-based medicine)?

This research is important because, as a patient with a chronic illness, I know what it is like to be on the receiving end of somebody who treats you like a number versus someone who treats you like a human being – someone who uses EBM versus someone who uses NBM. I am acutely aware of how the

narrative can affect a patient's treatment for the better and how it is possible for EBM to completely miss its mark. Furthermore, there has been a lack of more contemporary information on this topic and I would like to contribute and keep this topic as relevant as possible based on the evidence I have available to me. There is a potential for NBM to have a lasting impact on the medical profession.

There was a lack of more recent research so I was unable to ascertain how NBM has impacted the medical world today. While there are a number of articles written on the topic from when it first emerged from a Western perspective as a field of study, as of the time of this writing, there is limited contemporary information available. With the information I did find, I was able to ascertain the importance of NBM as it was relevant to my specific research questions. While NBM is especially helpful to chronically ill patients, there was a lack of research on that particular topic, and so I was unable to explore it further. There was not, however, a lack of critique on narrative-based medicine. There are many who oppose NBM and believe it to be more of a hassle and a hindrance to doctors rather than being helpful. If I had more time, I'd like to talk to other chronically ill patients and discuss with them their opinions on NBM vs. EBM and how valued and heard they feel as a patient. However, due to time limitations and my own chronic illness issues, that is not a viable possibility.

I intend to use this research to evaluate the efficacy of narrative-based medicine and its current role in the medical system. Given its benefits, I find it to be a worthy field of study and very efficient and altogether better way of evaluating a patient's needs for their illnesses. In the following chapter I will describe the findings of my study.

CHAPTER 4

RESULTS

For this study 11 articles related to narrative-based medicine were reviewed, including 3 with an experimental design. These articles were published between 1999-2018. While not all these papers describe experimental studies, they were written by leaders in this emerging field of narrative-based medicine. This was also the conclusion of authors of a systematic review of research studies using NBM techniques.

This study uses these theoretical and experimental publications to answer the following research questions: What are the pros and cons of narrative-based medicine (NBM)? How does NBM differ from evidence-based medicine (EBM)? How can NBM be integrated into the current EBM system of medicine?

Q1: What are pros and cons of NBM?

NBM allows doctors to integrate the patients' own stories and perspectives into their plan which improves the overall quality of care. This results in improved patient satisfaction as "they feel validated and their trust in the profession is reinstated" (Bakht, 2017). There is a better doctor/patient relationship, which is especially important for patients with chronic illnesses. More trust means a better rapport and more honesty about symptoms, causes, and effects. This approach also allows doctors to learn how their patients best understand things. They are therefore better able to explain what is going on when giving information (Bakht, 2017). With NBM, the chances of receiving an accurate diagnosis the first time around increase. It has also been found to reduce hospitalizations, reduce the number of "expensive, unnecessary tests and increase patient adherence to health promotion and disease prevention measures," (Bakht, 2017). It allows a patient-centered approach so that the patient's experience is included in determining

the best treatment plan (Kalitzkus, 2009). Studies show that two minutes of listening is enough for 80% of patients to recount their concerns, and out of 335 patients only 7 needed more than 5 minutes (Kalitzkus, 2009). "...narratives can have a healing effect – both in listening to the stories of others and in telling one's own story," (Kalitzkus, 2009).

However, doctors typically have a "we-know-best" attitude and some may be unable to admit when they're wrong or don't know something. This also leads them to generally not listening when you tell them you think something's wrong if it's not obvious. They also tend to take care of what the symptom or effect was, based on what the evidence tells them, and leave the cause for someone else. For example, if my leucine levels are high because I've been under a lot of stress recently and reached my stress limit. A doctor may just tell me to lower my leucine intake from food instead of realizing the root cause was the stress, not how much I was eating. Some doctors also consider it too taxing, putting added work into their already hard-to-grapple workload. Some, also, may feel unqualified to use this approach without prior training because physicians currently aren't trained and it also is time consuming with the way medicine is currently practiced which doesn't allow physicians enough time to sit and listen to patients. As learned from the intervention studies discussed below, NBM requires a good deal of training (Greenhalgh, 2005), support from administration (Greenhalgh, 2005), and a significant time commitment, (Cepeda, 2008; Greenhalgh, 2005; Wise, 2018). Results will not come easily or quickly, but given enough time and effort, they will come.

Q2: How does NBM differ from EBM?

There is no one accepted definition of NBM (Zaharias, 2018). "The definition arrived at in 2014 by a committee of international experts was that NBM is 'a fundamental tool to acquire,

comprehend and integrate the different points of view of all the participants having a role in the illness experience,'" (Fioretti, 2016, as cited in Zaharias, 2018, p. 177).

NBM involves paying attention to the narrative, representation of the narrative, and affiliation between narrative and patient, (Bakht, 2017). It also changes a doctor's role from "fixing faulty parts" to include humanism and professionalism, (Bakht, 2017). The purpose of evidence-based medicine (EBM) is to identify the best evidence using qualitative ways of thinking by means of "epidemiologic and biostatistical methods" (Misak, 2009). EBM purists will argue that a doctor using individual judgment over the established protocol derived from Randomized Control Trials (RCTs) is irresponsible; personal opinions or any element of subjectivity is frowned upon (Misak, 2009). "...EBM shifts focus of clinical practice away from reflection on individual patients and towards populations with unhappy results for patients who are outliers" (Misak, 2009 p. 393). Some competing clinical options are contradictory or incomplete making the risk-benefit analysis of treatment a gray area if looking just at data to make a clinical determination (Misak, 2009). Current medical students are not guided to make subjective clinical judgments and are instead taught to rely on protocols that EBM offers (Misak, 2009). NBM is learning about the patient and/or caregivers' perspective for what they consider to be research and training (Kalitzkus, 2009). NBM uses narrative as evidence and sources of knowledge beyond the EBM gold standard of RCTs (Kalitzkus, 2009). A narrative approach in medical practice is arrived at by understanding the narrative structure of medical knowledge, and narrative based practitioner-patient relationship. An argument for EBM is that the time that would need to be dedicated to incorporating an emphasis on narrative would decrease the number of patients a doctor can see in one day. EBM has gained a reputation of dismissing the importance of the individual.

Q3: How can NBM be integrated into the current EBM system of medicine?

I identified 3 interventions which attempted to integrate NBM into EBM.

Cepeda and colleagues investigated the effect of incorporating a structured narrative approach on perceived pain and sense of well-being in patients with advanced cancer (Cepeda, 2008). In this study, 234 adult patients with cancer reporting moderate to severe pain were asked to write about how the illness has affected their lives. This was a randomized, single blind controlled study taking place over 8 weeks. Patients were randomized into one of three groups: Group 1 (Narrative) was asked to write, while at home, for at least 20 minutes once a week for three weeks a story about how cancer affected their lives. Group 2 (Questionnaire) was asked to complete a pain questionnaire while at home. Group 3 was the control group, simply asked to attend weekly follow-up visits. Questionnaires were used to evaluate pain and sense of well-being. After 8 weeks, no difference in pain rating or general sense of well-being was observed between groups. However, 5 patients with a high degree of emotional disclosure reported a greater sense of well-being.

This study was fairly large and included all types of cancer. However, the intervention was limited to a written narrative rather than telling their story to an individual in a face-to-face meeting which may have limited its impact. All in all this study was important as it showed the effects on well-being that could be obtained. It's important to point out that this study had the biggest number of subjects, but was for such a limited amount of time, it wasn't able to show as much impact as it could have. Nonetheless, it demonstrates how NBM can be used as an adjunct to EBM to facilitate care by listening to the patient's voice.

Greenhalgh and colleagues (2005) investigated the impact of bilingual health advocate-led storytelling groups on blood glucose levels in patients with uncontrolled diabetes in under-served

areas of South Asia. The researchers faced challenges in training health advocates to provide diabetes education as well as storytelling techniques. Health advocates had difficulties in leading the discussions and the conversations were often chaotic. There, sadly, was not a lot of support from the health center administrators and so the program was on very unsteady legs. No changes in blood glucose levels were observed over time.

Here NBM was used in conjunction with EBM to improve blood glucose control in patients with diabetes. It showed how important it is to convince administrators of the value of narrative-based medicine. You need to have a good, strong, foundation that's willing to really put their effort into making this work in order for it to be effective.

In the final study, 86 adult patients with Stage III or Stage IV cancer were randomized into an intervention group (37) or a group with normal care (49) (Wise 2018). The intervention group was interviewed (45 minutes to 2 hours) about the way in which cancer is affecting their lives and how they are coping. All were receiving standard medical care (EBM). They were also provided with access to a website called MiLivingStory which is housed on the National Cancer Institute and American Cancer Society websites. This site provided information, planning tools and support groups, as well as tips on revising and sharing their story. A social network allowed participants to share their stories with others.

Primary outcomes included measurements of peace and meaning as well as depression, anxiety, and anger as assessed through validated questionnaires. Measurements were taken at baseline, 2 and 4 months. No significant differences were found between groups at 2 months. At 4 months, a positive effect was found for peace and a trend towards a positive effect was found for depression.

Strengths of the study included subject selection, one-on-one interview, and supportive staff. Limitations included the use of telephone for the interviews and on-line support rather than in person. In addition, the sample size was small.

This study provided evidence that providing narratives may have a positive effect on mood and outlook of advanced cancer patients. Further interventions with in-person interviews and larger sample sizes may show a greater effect.

CHAPTER 5

DISCUSSION

Including narrative in patient care is not a new concept, but modern medicine has pushed it aside as more and more technologies have been developed. The purpose of this research was to explore the differences between NBM and EBM, understand its benefits and challenges, and investigate ways in which it can be implemented and possibly integrated with EBM. I have concluded that this emerging concept is critical for patient care. From a personal perspective, I became interested in this topic as a person with a chronic disease. My body is not able to metabolize branched-chain amino acids (BCAAs) and the main treatment is a very strict diet. Regular doctor visits have always been a part of my life. I recognize that if my doctor was simply to do a blood test to check my blood BCAA levels they would only know one small piece of what is going on with me. It is important to assess whether my levels are high because I have not been following my diet, or because I'm stressed, or because I am sick. If I have not been following my diet, it's important to understand why. The only way she would know about this is by talking to me and listening to my narrative.

Only a small number of intervention studies have been done using NBM. All of the studies that I reviewed used NBM with EBM. NBM was found to improve positive feelings among cancer patients (Wise et al., 2018). It helped alleviate pain for patients with rheumatoid arthritis and helped increase lung capacity in asthmatic patients (Kalitzkus, 2009). Little improvement was shown after 8 weeks, but improvement began to become evident after 16 weeks.

In order to strengthen medical care with the inclusion of NBM, some long-term changes need to be made, and a strong foundation of NBM is needed. Administrations need to be behind

using NBM as a valid means of medical treatment, and doctors need to be taught more about NBM and how to properly listen to their patients and analyze what they are saying to them. Although this would be a gradual process, integrating NBM into mainstream medicine would benefit both doctors and patients. Doctors would be able to better understand where their patients are coming from and patients would feel heard.

Especially surprising were the results of the quantitative studies. The studies, which were in my opinion too short, either showed very little or no improvement on the patient's well-being or emotions. It is possible they were unable to show an effect because there were too few subjects in the studies. The largest study had 234 subjects. The short duration of the studies could also have been a problem. The longest that a study was conducted for was 16 weeks. In my opinion, this is not sufficient enough time to be able to see a significant change. It's also possible that having face-to-face interviews would have led to better results.

So, What?

NBM is indispensable for *all* patients, not just patients with chronic illnesses. It increases empathy in doctors and compliance in patients because they now have a say in their treatment and they feel like the doctor now understands how the disease is affecting them as an individual. They get to understand why the doctor feels such-and-such is necessary instead of just having to go with it. Doctors are better able to understand their patients and their illnesses. They now understand the individual ways that they present and how individual narratives influence the way patients navigate their illness. NBM also increases positive feelings in the patient, making them feel heard and listened to instead of feeling like they are just a number. "...[sharing] illness experiences have improved wellbeing among seriously ill patients" (Wise et al., 2018 p. 200), meaning that the very act of storytelling itself is one that is therapeutic.

While some of these narrative interventions did not see results until months in, that does not mean that there was no benefit to NBM. It's entirely possible there was an unmeasurable benefit. NBM is very important for numerous reasons that assist both the doctor and the patient in achieving their desired outcomes. It is a unique method that cannot be replicated through evidentiary means, and because of that it deserves to be regarded on its own merits.

Now What?

Now, we need better designed studies with longer duration in order to prove the benefits of NBM. Columbia started a Master's program in NBM with the belief that all clinicians would benefit from learning this technique. We should be implementing NBM in medical schools all around the country (if not the world), possibly even as early as pre-med programs. The methods of NBM should be taught as a prerequisite for medical school, meaning that all students entering into the medical field would be versed in the methodology of narrative-based medicine.

Future studies could include taking Launer's list of questions and going to interview patients with them (Zaharias, 2018). The questions are broken into two groups: exploratory questions (ex. Is there something you are worried about?) and ones inviting change (ex. What would happen if…) (Zaharias, 2018). These questions stand to get the patient talking about how they feel about the situation and their experience. The way they answer these questions will help the doctor understand what they are experiencing on the surface and the subtext based on how they describe it. Tools like this serve to not only put the patient's perspective at the forefront, but also offer insight into how individual understanding of one's situation may impact their relationship with illness and medical care.

Additionally, further qualitative studies with longer periods of observation and interaction should be conducted, with emphasis on face-to-face interviews. It is important that

some of the research is done through in person interactions, as it is the best way to understand and capture the nuances in speech and body language. Repeated studies with participants over an extended period of time—beyond 16 weeks—would also help to get a better understanding of the longer-term benefits and complications associated with narrative-based medicine.

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