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Ethical Considerations Related to Narrative Medicine

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Abstract

Narrative medicine is of great significance in the area of health care, which underpins the ability of acknowledgment, absorption, and interpretation according to which plights and stories of patients are extensively considered for the commencement of actions. It reflects the manifestation of a model that entails effective medical practice with the aim to achieve best possible outcome. Adopting different approaches to narrative medicine (such as the method of close literature reading and reflective writing) facilitates with the opportunity to examine and explore central medical situations. Narrative medicine is responsible for the development of effective communication between patient and healthcare professionals, alongside inaugurating substantial discourse with the community regarding health care. With the advancement in clinical conditions, the scope of narrative medicine has become a growing need, and thus, several developed countries have already included narrative medicine as an integral part of health care. However, the major ethical problem associated with patient narratives is the use of data with intention other than treatment which may result in maleficence. Therefore, the practice of narrative medicine requires balancing all the aspects of health care against any possible harm.

Keywords: narrative medicine, patient narrative, narrative ethic, ethical concerns, patient-physician relationship

1. Introduction

Patient-centered medicine is an approach that has been greatly integrated into the area of evidence-based medicine and is regarded as an essential attribute underpinned by health care [1, 2]. The description of patient-centered approach put forth by proponents depicts that facilitation of care services in the light of this approach generates numerous opportunities for honoring preferences of the patient, their values, and needs [3]. The patient-centered approach

is responsible for applying a biopsychosocial understanding rather than entirely focusing on biomedical knowledge [4]. The major benefit entrenched by the approach is the development of a robust partnership between healthcare professionals and patient [5]. Currently, several studies have covered patient-centered care services and the impacts resulting from it on processes and outcomes of care by extensively emphasizing on the relationship between patient and care facilitators. Nevertheless, much of the patient's experiences result outside the office of a physician [6–8].

Interaction of patients with healthcare professionals has reached beyond the visits to physician's offices through the inclusion of virtual medicine, support from a peer group, and a variety of information as well as the incorporation of communication technologies for the purpose of providing support to care [9]. In addition to this, the ability of a clinician or team of healthcare professionals for the facilitation of patient-centered care is aligned with the setting in which they function (i.e., a small setting for private practices, a large hospital, separate care facility for urgent purposes, or assimilated group practices with multispecialty). On the other hand, the efforts for making the environment of healthcare vigorously responsive to healthcare needs of patients, alongside largely considering their preferences, will assist in the attainment of best possible outcomes if they are encompassed with a profound sense of understanding about the factors through which patient-centered care is promoted or impeded [3, 4]. Moreover, such efforts require a combination of patient-centered care with the system of a healthcare setting as a fundamental property [10].

With the passage of time, a significant shift in medical practices has been observed as a result of tremendous advancements, which, in turn, is improving the quality of life of people around the world. In this regard, narrative medicine has emerged as an essential new set of skills that enhance abilities of healthcare professionals [11]. Narrative medicine is accountable for benefiting healthcare professionals as well as patients with the duration of treatment by providing meaningful ways. The narrative medicine practice has been projected by the aid of a model that entails aspects of reflection, empathy, trust, and professionalism [11]. The basis of narrative competencies is entrenched with the capability of acknowledgment, interpretation of the absorbed information, and acting accordingly to the plights and stories of other individuals [12]. Methods that are entailed with storytelling, reflective writing, and analysis of literature can be utilized for practicing narrative medicine and for the development of narrative competencies. Furthermore, incorporation of narrative medicine approaches in medical education, such as exercises that require illness narrative writings as a method for teaching patient-centeredness, empathy, and humanism of great significance [13].

2. Narrative medicine

Narrative medicine has been developed by a combination of theoretical and operational approaches that have been increasingly applied in the current practices of health care. The existence of this approach is enrooted around 30 years, after which its application has been extensively carried out in daily medical practice as an effective tool for the collection and

interpretation of information [11, 14]. The act of clinical method is significantly interpretive that consists of narrative skills for the integration of such stories that overlap with one another and are expressed by patients, healthcare professionals, and test reports. Medical narrative practice aims to comprehend the experience of a patient in regard to his/her feelings and perception about the process [11, 14]. Several scholars have highlighted that listening to the stories shared by a patient is an efficient tool for enriching the knowledge depicting the physical and psychological condition of the patient, alongside offering information that can be utilized for the formulation of diagnosis. Therefore, physicians and other healthcare providers are required to align their daily practices with narrative medicine [10, 11].

Simultaneously, narrative medicine is a descendant that has resulted from the area of literature and medicine, and is parallel to patient-centered care. Medical practice can utilize narrative skills for preserving recognition, absorption, interpretation, and making progress by the help of illness stories told by patients [13]. In addition, narrative medicine, which, in turn, is process-based and interdisciplinary for examining clinical conditions, therapeutic relationship between healthcare professional and patient, and meaning underpinned by health care [15, 16]. The methods of narrative medicine have facilitated with the demonstration that tends to enhance the consistency as well as awareness regarding what other perceives while reducing the level of burnout and fatigue related to compassion [17]. Rapid development in health care has been noted due to extensive implementation of narrative medicine. In several schools of medical practices in the US and Canada, the students have experienced significant improvement in their learning skills by the utilization of narrative methods [18, 19].

The conceptualization of narrative medicine is based on three aspects, which are considered as the foundation of clinical practices. These aspects include investing attentively, representation of facts, and affiliation with the practices and patients. The implementation of these factors provides an opportunity to form an authentic contact between a patient and healthcare professional as a prelude resulted from action. Each of the mentioned factors is combined with in-depth knowledge, competencies, and attitudes for enabling healthcare professionals, their colleagues, as well as patients so that they can undertake the development of effective partnerships on the basis of care and recognition [20].

In context to investing attention, it is regarded as the state that requires a rigorous focus on an individual, written text, or artwork for the purpose of enabling perception without the manifestation of distraction [21]. However, the factor of representation deals with linguistic discussion, which can be put forth in visual form parallel to the formless experience of complex nature for perceiving, reorganizing, and communicating to self and other people involved in the process of care [20]. On the other hand, affiliation is entrenched with a shared commitment and its development by mainly aiming patient's well-being. The attainment of affiliation can be carried out by the formation of meaningful contacts among physicians, patients, and colleagues. The simultaneous implementation of attention and representation leads the participants to sustain affiliation for achieving patient compliance and goals of healing within the clinical practices.

In addition to conceptual factors of narrative medicine on the basis of which the commencement of reflective writing takes place, different types of narratives are integrated according to

the clinical condition presented by a patient. In some cases, the situation is also considered for the implementation of a narrative process [22]. For the purpose of facilitating education to healthcare professionals and patients, narratives often play the role of memorable, which, in turn, are formed by experiences for encouraging reflection [13]. The following are some prominent examples regarding different types possessed by narrative medicine.

2.1. Medical interview

Medical interview is the type of narrative medicine which is coined as the most adaptable and beneficial tool for diagnosis and treatment. Conversely, interviewing a patient is also entailed with significant difficulties due to the requirement of physician's active involvement and efficient skills in the area of clinical studies [23]. The demands projected on healthcare professionals are intellectual as well as emotional. The skills to conduct analysis and diagnostic rational must be incorporated in balance, alongside the presence of interpersonal skills for the establishment of patient rapport and the development of better communication with patient [23]. In the area of medical practice, medical interview is responsible for providing an essential pathway for the establishment of an assisting relationship of commitment and trust. The process of observation carried out by verbal and nonverbal means facilitates with important information regarding the patient as an individual. Emotional concerns of the patient are assessed by the aid of behavioral projections of a patient during the interview such as, posture, facial expression, and gesture. In addition to this, the interview consists of face-to-face meeting which either can be video-recorded or audio-recorded [24]. During the interview, the clinical practitioner is able to understand patient's reaction about the manifestation of an illness and how the patient is relating his or herself with others. Another critical element that is widely considered during an interview is the style of communication and behavior of the healthcare professional during the process of interviewing [25].

2.2. Medical history

This type of narrative medicine is underpinned with journal writing that holds medical history and all the aspects related to it, along with the science related to health by keeping the goal of extending the knowledge and understanding of the area. In addition to this, medical history also requires the highest quality of historical studies. Symptoms are included in the medical history, which is reported by the patients or their family members in the form of related medical complaints [26]. The symptoms are then compared to clinical signs; those are determined by directly examining the part described by medical personnel. Conversely, if a patient has a psychiatric condition, then an in-depth and lengthy medical history will be attained, along with a number of details regarding the life and activities of the patient that are relevant to the formulation of an effective plan so that the psychiatric illness can be managed. The information collected through the implementation of this approach, in combination with the physical examination, provides the healthcare professional with a chance to carry out diagnosis and to plan effective treatment [24].

2.3. Literary narratives of patients

The literary narratives provide insight into a diversity possessed by alternative forms and situations associated with medical practices, which tempt the reader to carry out the application of his skills of interpretation for differentiating between obsolescence and tradition [27]. In addition to this, literary patient narratives aid contemporary medicine by providing clarity about tradition, alongside aligning itself with future possibilities that are brought into the present from the past [28]. On the other hand, literary narratives could cause a reduction in valuable evidence of medical practices that vary from those presented by physicians according to their experience [27]. This type of patient narrative assists in reflecting on values entrenched by the clinical events. Some healthcare professional belief that literary narrative is a medium through which readers are provided with a broad vision that develops empathy toward the patient, as well as compassion for serving human and enhancing sense of ethics [29].

2.4. Classical illness narratives

Patient stories allow healthcare professionals to understand the sufferings and feelings experienced by the patients and their family members. These stories are presented by combining biographical context with the social context of the clinical condition for the purpose of suggesting strategies to cope. These narratives are of great potential for assisting a person with personal development [30].

2.5. Patient-physician narratives

Patient-physician narratives are articulated and formed by obtaining information about the illness, and the process associated with the condition. The experience of patients regarding the clinical symptoms is then interpreted by the utilization of medical knowledge possessed by the involved healthcare practitioners, which, in turn, lead to an efficient diagnosis and therapeutic intervention [31]. After the diagnosis of the condition, the narrative of the patient changes about their personal experience, as the perception of medical diagnosis and therapeutics plays a major role on their sensations. This type of narrative is frequently used during the treatment of cancer [32, 33].

3. Expected outcomes of narrative medicine

A narrative is entrenched with the potential for informing, revealing, healing, and inspiring through different ways, which help in the dissemination of best possible outcomes [14, 34]. With the addition of a human lens, experiences related to health care are enriched, without causing detraction of the important facts and time frames [35]. Similar to their patients, some of the healthcare practitioners have involved in the process of learning so that they can effectively attain help for verbal representation about they experience throughout their medical practices. Several physicians write narratives about their practices for keeping records about how they interact with other people. Narratives help the doctors to illustrate aspects related

to their emotions and personality and the care they provide to their patients. Some of the authors have reported that narrative writings have helped them in comprehending the ordeals associated with their patients by aligning their lives with the people who have disease [35, 36].

The utilization of narratives entailing healthcare professionals, stories of patients, film, and literature is extensively gaining popularity in the area of medical education. However, there is a profound need to encompass conceptual framework so that these efforts can be provided with significant guidance in curricula of medical schools [19]. Through interpreting their observations, the doctors, who are also the writers of patient narratives, can unveil great truths that are encompassed by the illness course regarding an ordinary life of a person. Dr. Rita Charon, a director of the Narrative Medicine Program at the Columbia University College of Physicians and Surgeons and a clinical medicine professor, is well known for her immense contribution in the area of narrative medicine. Dr. Charon described that there is a profound need of physicians by the people who are presented with a clinical condition [11, 14]. The underlying reason for such need is that physicians are able to understand the disease and facilitate with high quality care services. People have a perception that reflects physicians not only provide treatment of their illness, but also accompany their patients throughout the course of treatment [11]. On the other hand, utilization of patient narrative for designing healthcare services, to conduct research, or for providing medical education, is encompassed with both pros and cons. Therefore, significant consideration is required by keeping rules and regulation in mind before using patient narratives for the stated purposes [37]. Following are some of the major pros and cons associated with the patient narratives.

3.1. Pros of patient narrative

1. The method of the patient narrative is significantly conventional due to which the implementation of such approach is extensively practiced [21].
2. The method underpins great aspects of flexibility and can be utilized in several clinical settings [21].
3. Nurses can also record the chronological events related to a situation through the use of this system [38].
4. The narrative type of documentation provides assistance to the healthcare professionals by painting a picture that elaborates care services facilitated to a patient for an extended duration [21].
5. Patient narratives can be easily used in emergency situations due to the aspect of quick charting [38].
6. Patient narratives can be easily integrated with other methods of documentation (i.e., flow sheets) [21].
7. Patient narratives provide significant opportunity to develop logic and motivations regarding patient's condition that otherwise appear irrelevant [39].

3.2. Cons of patient narrative

1. The notes taken in the form of patient narratives depict subjectivity and the approach also lack nursing evidence related to analysis that plays an important role in the decision-making process [26].
2. Significant limitations can be noticed in patient narratives, which entail perceptions and perspectives [38].
3. Patient narrative notes are not structured and are often presented in a disorganized form without any continuity [40].
4. Scanning notes may consume time for searching fundamental information depending on the feature of disorganization [41].
5. These notes can be considered as task oriented, alongside incorporating less or no focus on evaluation [26].
6. Healthcare professionals are often encountered with frustration at the time of tracking a particular aspect associated with the condition of a patient [41].
7. Patient narratives may be difficult for keeping the track of patient's condition and progress due to several documentation processes carried out by various healthcare practitioners on different days or shifts for registering the similar event [26].

The skills required to use narratives in healthcare practices are of great importance. In this context, teaching methods have been designed to prepare efficient practitioners. Some of the prominent medical education programs have been assimilated in "narrative medicine" or "narrative-based medicine" for the purpose of teaching particular aspects embedded by narrative competence [18, 19]. The mentioned type of educational training tends to encourage healthcare practitioners as well as students by improving their writing skills through the use of a nontechnical language so that they can keep the record of their patient's condition [22]. In addition to this, patient narratives are also widely used by healthcare patients for attaining help so that they can disclose and understand their state of mind toward their patient's condition. The importance of narrative medicine programs can be evaluated from the fact that they promote rigorous training through which the learners appropriately encounter how to read literary texts for further supplying healthcare professionals with the interpretative tool, alongside creating a sense of the patient's stories. At some occasion, healthcare practitioners provide encouragement to their patients for describing their condition in the form of a written text. The narratives were written by patient project significant interruption of the text flow and assist the healthcare professionals in demonstrating therapeutic benefits associated with the narration to the patient [42].

Narrative medicine curricula and projects have been proliferating throughout the US, Great Britain, Canada, Europe, and Australia [43]. In the US, the narrative medicine study is regarded as the multidisciplinary area, while the master's program curriculum of narrative medicine embeds fundamental courses that are responsible for providing the students with an in-depth understanding of the experiences related illness, the equipment for closely reading and

writing [44]. On the other hand, focused narrative courses are used in the areas such as genetics, palliative care, social justice advocacy, and field work. The narrative medicine study provided in Great Britain emphasizes on the investigation of patient stories for understanding symptoms and experiences of the patient in case reports and clinical literature. The medical narrative students are trained to comprehend interfaces related to descriptions and images, such as the textual presentation of a disease, text written by a patient, and diagnosis resulting from close reading [35].

The educational programs of narrative medicine in Canada enhance the ability of learners to apply best practices by analyzing the principles deep-rooted by narrative, alongside the manifestation of arts-based research in the area of health care. The educational programs encourage the students to carry out utilization of their investigative and interpretive skills that are required for closely reading, actively listening, visual literacy, and reflective writing for enhancing diagnosis and therapy [45].

Regarding the narrative medicine programs in Australia, the area of education is making a tremendous progress by dispersing awareness among current and future healthcare professionals about the impacts of narrative medicine in practice. The master's program of narrative medicine strengthens the attainment of best possible outcomes in several fields, including medicine, social justice, public health, and clinical experiences of an individual [18].

4. Challenges of narrative medicine

An approach of narrative medicine plays a vital role in facilitation of healthcare services. The rapid evolution of modern medicine tends to contribute to the challenges posed to narrative medicine due to the requirement of profound attitudinal and technical modifications. These changes are of great significance and are difficult to apply. During its initial stages, the practices of narrative medicine can be converted into a destabilization phase, which, in turn, position a capable healthcare practitioner in doubt about his or her practices [46]. Another major challenge that can be encountered during the integration of narrative medicine include is acknowledging when to discontinue. Healthcare practitioners who closely associated themselves with the notion of narratives often forget to realize that their position is not safe [46].

5. Ethical concerns

The ethics required for medical narratives are considered as the act of evaluating language that is aligned with perceptions, thoughts, and sensations experienced by the teller so that others can relate to what he or she is trying to describe [14]. The individual who receives narrative of another person also receives virtue of the teller, which, in turn, plays the role of an inter-subjective bridge to the ethics of narrative medicine. On the other hand, the major ethical problem associated with patient narratives is the use of data with intention other than treatment which may result in maleficence [14]. In today's world of technological development,

narrative ethics and non-maleficence require balancing all the aspects of health care against any possible harm [47].

Although narrative medicine has emerged as ubiquitously identified the domain of study, the manifestation of ethical concerns reflecting maintained of privacy and confidentiality of patient's data has raised several questions [12]. The study of Nelson depicts that the framework of medical ethics is regarded as an essential part of an individual's professional identification, instead of projecting skills and knowledge. Simultaneously, the critical aspects underpinned by the identity of a healthcare professional are operating within the formal prospects in more subtle way. The authors also stated that education and use of narrative medicine are responsible for establishing "moral enculturation," which possesses a subtle part of formal teachings of ethics [48]. Moreover, any attempt that is put forth for the development of comprehensive syllabus of ethics must allow the manifestation of wider setting of different cultures within which the syllabus must be implemented. For the purpose of fostering ethics among students, formal as well as informal syllabus must be addressed through the aid of syllabus planners. However, Goldie states that without an adequate consideration, physicians may be in danger of objectifying and manipulating patients in accordance with an egocentric self-interest [49].

The current form of narrative medicine provides a small space for aligning the properties of critical reflection or examination of larger inequities and violence. The violence is of structural nature that takes place within a healthcare setting in the light of which feelings of people are neglected. Marini illustrates that narrative medicine lacks consideration of the narrative limits, particularly ignoring the contexts related to suffering, trauma, and oppression. In other words, people are often bounded by certain experiences due to which their assimilation with the storyline does not match. Experiences gained by a human cannot be narrated in a single story as a result of which gesture and metaphor can be integrated as an effective means for the development of better communication between patient and healthcare professional [26].

Of course, confidentiality protections play a fundamental role in the practices of patient narratives for patients and people who are involved in the process of writing. In this context, a number of questions have been raised such as, does patient narrative lead to the promotion of new learning and self-understanding or is it the procedural intention toward self-justification? [20]. However, regarding the ethical concerns, the practices of patient narratives entail alteration or removal of personal data through which an individual can be identified. Several healthcare professionals have encountered resistance from patient as they fear that their personal information could be used for other purposes or personal benefits of the healthcare settings [48]. The pitfall of data breaching is assured by several national regulations (i.e., Health Insurance Portability and Accountability Act) [50]. On the other hand, the International Conference on Harmonization (ICH) has proposed a set of guidelines regarding the content and structure of patient narratives. According to their guidelines, it is mandatory to provide an explanation of possible adverse events or other adverse effects that can be investigated for clinical importance [22].

The notion of ethical concerns related to patient narratives is responsible for contributing to complications in decision-making process, which is the essential step in designing a treatment plan. It is necessary for the healthcare professionals to maintain significant balance between

narratives of patient and their decisions [14]. Simultaneously, narrative is presented with the requirement of developing a relationship of confidentiality through respecting privacy of patients so that they can be encouraged to seek care services. For the purpose of sustaining confidentiality, the obligation associated with it prohibits disclosure of the patient's information presented in a narrative form [51].

6. Discussion and result

Narrative medicine is largely utilized in health care for the promotion of the integrated, systemic, and multidisciplinary development of an approach through which populations can be facilitated with care, regardless of their age groups [11, 14]. The stories illustrated by patients and healthcare professionals, along with their way of representing, perceiving, and experiencing can lead to the reduction in the risk associated with inappropriate clinical tests and treatments [14]. The area of health care has always been encountered with significant saturation, alongside the presence of narrative knowledge. Over the past few decades, an increase assimilation of writing into research and teaching has been observed in the form of narrative medicine [19, 23, 45]. In addition to this, the most commonly occurring ethical concerns is encompassed with barriers and uncertainties associated with truth elaborating, along with cultural and familial conflict, as well as futility [40]. In this regard, physicians and other practitioners' function by offering strategies to develop effective communication with patients and their family members.

In the context of the current practices of narrative medicine, different types of narratives are incorporating the power of appreciation and analysis in the clinical studies by the aid of storytelling [43]. Team of healthcare professionals is at the forefront for facilitating with information based on prognosis. Shortly, narrative medicine would be able to separate its root from assumptions and methods utilized during the process of history taking as well as for eliminating the possibility of several conflicts. Medical practitioners and educators are gradually including many approaches and techniques that are underpinned by literary studies, philosophy, history, along with other disciplines of humanities for bridging the gap that projects a lack of recognition and understanding a particular illness and the pathological dimension associated with it. However, there is a profound need of educating students of narrative medicine about potential ethical concerns, which can lead to negative outcomes of health. Ethical concerns mostly deal with information breaching as a result of which several patients avoid to participate in the process of narrative writing. Therefore, it is the fundamental responsibility of the healthcare practitioners to develop a therapeutic relationship with their patients so that the flow of information can be maintained [40, 47, 48, 52].

Narrative medicine has contributed greatly by aligning trustworthiness and compassion with medical ethics. Competency of practicing narrative medicine and a framework of narrative for medical ethics can lead to the enhancement of ethical considerations at various stages including recognizing an ethical issue, oral or written form of the issue, ethical case interpretation, and selected interpretation with its validation. Ideally, narrative medicine would assist healthcare

professionals in the prevention of ethical dilemmas by increasing the chances of recognizing the issue at its initial stage and resolving it [40, 49].

Narrative medicine should be explored more deeply to decode techniques through which clinical conversations can be shaped. The noticeable proliferation of writings in the past years has emanated a new perceptive of health as well as social care and different situations associated with it. The narrative medicine not only sheds light on metaphors possessed by various clinical conditions but also provides direction to imagery presentation of diseases in a graphic novel and films. The best possible health outcomes are obtained when health care and social work are combined with ethical narrative medicine practice. The resultant of narrative medicine is capable of eliciting and functioning with illness stories and worlds depicting the fractured life of a person by acknowledging the importance of communication through telling and listening to stories [11, 14, 40, 53].

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