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# A NEW HEALTHCARE PARADIGM: 'PATIENT HEALTH NARRATIVES' ENHANCING PATIENT ENGAGEMENT THROUGH SHARING STORIES

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## ABSTRACT

Patient storytelling, called pathographies, is an emerging patient engagement trend in healthcare today between patients, doctors, nurses and caregivers. Stories have importance because they create opportunities for people to share and learn from one another's experiences, evoke emotions and build friendships. A brand new paradigm called 'Patient Health Narratives' will enhance patient engagement by having patients share their written stories (narratives) online and interact with an online audience. Some written stories are brought to life in conjunction with a patient video interview or commentary. This new paradigm provides patients with an interactive forum to express their illness experiences to interested parties and become part of an online non-medical supportive community of fellow patients who have, or are undergoing, similar experiences. Patient Health Narratives will also aide individuals facing surgery to allay fears and have questions answered by other patients or caregivers through storytelling.

**Keywords:** Patient Health Narratives, pathographies, new patient engagement technique, story-telling, narratives, new healthcare paradigm

## 1. INTRODUCTION

"A story has no beginning or end: arbitrarily one chooses that moment of experience from which to look back or from which to look ahead."

— Graham Greene [1]

Stories are very important because "there is an intense longing for human connection" [2]. Telling stories creates opportunities to share and learn from each other's experiences, arouse emotions, and build new friendships. From the perspective of healthcare, stories not also bring doctors, nurses care givers together with patients, but they can also link patients and a sympathetic audience together by sharing stories to create a sense of community. Hearing the voices both of the reticent and those who are ignored when they do speak up has become of the most essential, but presently "underappreciated, tasks in health care ethics today" [2].

The leader in transforming healthcare today is 'patient engagement' which has been labeled "the blockbuster drug of the century" [3]. This is creating new collaborative possibilities for patients who want to relate their health experiences [4]. Patient Health Narratives is an innovative concept designed to open communication online between



patients and an interested and sympathetic audience to build a sense of belonging to a community that cares. The new paradigm builds on the concept of narrative ethics developed from doctors, nurses, and ethicists who began to listen with interest to patient pathographies, which are narratives that offer “voice and face to the illness experience” [5]. Pathographies transpose the person behind a disease to the forefront to provide a learning experience for caregivers and fellow sufferers [5], for not only do the “human qualities of the affected individual persist, the self persists” [2]. A patient’s desire to be valued as a whole person with feelings and hopes is always present.

The unifying element of narrative ethics was the initial recognition that narratives are significant in health care [2]. The narrative dimensions of how patients relate their experiences about their illnesses, how doctors or ethicists translate those experiences into their own words, how interns frame the experiences when they move about their rounds [2], all evoke emotions and conclusions from listeners. These narratives are profound and define the importance in ethics and patient care [2]. The difference between Narrative Ethics and Patient Health Narratives is that the former involves patient interaction with caregivers. The latter presents a patient’s written story, intermixed with patient digital storytelling (video) [4], and interaction with an online audience.

In the healthcare industry, there are few options to for patients to share their emancipating stories and allow others to step into their lives. Patient Health Narratives allow patients to share, acknowledge and honor their illness experiences [2]. Hence, the importance of Patient Health Narratives is that they open a vista of information and experience by online sharing and videos. Additionally, there is also interaction and feedback which may lead to the formation of an online community of patients. Individuals can bond through their experiences outside of a hospital or clinical setting. This is accomplished through deep meaningful conversations and patient story-telling that articulate patients’ health goals and challenges. These patient dialogues become a ‘living’ document filled with personal details. Sharing stories allows patients to engage in interactive social support while concurrently dissuading feelings of isolation.

In some instances, when patients tell their stories, they reveal concealed barriers to their health and recovery [6]. A patient’s anxiety and fear of surgery (tomophobia) [14] can be so terrifying that he/she can exhibit physical symptoms, “such as a racing heart, nausea, and chest pain [12]. These patient fears can emanate from the fear of the unknown, having unpleasant experiences with previous surgeries, high-risk of awareness (waking up) during surgery [15], fear of an alteration in the body’s appearance (mastectomy), or, in the case of prostate surgery, a loss in sexual function. The worst patient fear is mortality [12]. These fears and anxieties are particularly acute when the patient is on a waiting list for surgery or transplant [13]. “Being able to discuss concerns openly with someone who is not directly involved” such as a patient who has already undergone a similar procedure and can give answers, explanations, and assurances, “can be very therapeutic” [12].

Patient Health Narratives would assist preoperative groups to provide patients with the opportunity to discuss their potential fears and concerns regarding their upcoming surgery. Discussing this with other group members allows patients’ own concerns to be normalized. It also provides the therapist an opportunity to dispel some myths that the patient may have regarding surgery, and to help the patient use cognitive strategies to cope with anxiety-provoking thoughts. [16]

Story-telling is nothing new. “We live by stories, and they’re what give sense to our lives” [2]. The disciplines of psychology and law have long respected the power of narrative and how it affects lives, and now medicine is following suit [2]. When story-telling becomes an interactive process, as in Patient Health Narratives, it can provide individuals a means to talk about “pivotal life events, justify choices, examine reality and find meaning in experiences” [7]. Storytelling is also emancipating, allows “bonding with others, validating and affirming experiences, venting and catharsis, resisting oppression and educating others” [7]. Top marketers and communicators use storytelling to connect and motivate audiences to act [8]. The Center for Digital Storytelling created a process in the 1990s to generate 3-to-5-minute short films by synthesizing “still images, video, voice recordings, music or sound, and text [4]. Even the Web of Stories offers listeners the opportunity to hear some of the most notable people of our time relating their life stories [9]. In 2011, Chen [11] suggests one possible method for story-sharing, in which doctors and patients would have access to Web sites that would “match patients to videos of similar patients recounting their own experiences with the same disease.”



Sometimes when everything in life is going right, something goes wrong, such as being suddenly diagnosed with an illness. In literature, this reversal of circumstances is called ‘peripeteia’ [2]. Coping with peripeteia and life’s sometimes challenging reality by story-telling helps restore legitimacy and expectancy to peoples’ lives [2]. Narrative is indispensable in learning how patients got to their present condition just as much as the story of moving toward the future [2]. Building a patient relationship can be made tangible by using a convenient, user-friendly interactive online platform where patients can tell their stories through print and/or videos. The interactive capability can elicit a broader picture of patients’ experiences with feedback through a peer-to-peer system of reviews and opinions. According to Socrates, the greatest peril in our lives is the failure of people to participate in the “dialogue between reader and text or between the self and other, to immerse themselves in the stories that surround them” [2]. This dialogue is where humans practice the “rhythms of asking and answering, speaking and listening, feeling and thinking, [and] giving and receiving” [2].

“A story is inside of us all. Each word and sentence is alive and we grace the pages to keep it from dying.” — Aisha Mirza [10]

## 2. CONCLUSION

Patient Health Narratives is a new paradigm using an interactive online approach to engage, empower and inspire patients by allowing them to share their stories and experiences. The new paradigm will provide an opportunity to get and give advice, and offer encouragement to others in similar health situations.

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