Once Upon …Our Time: Narratives in Health Education

Abstract: Narrative stories and testimonials from patient and healthcare professionals are a health literacy tool used to inform, engage and raise awareness. Stories focus on experienced reality and become relevant and engaging to audiences in different ways than traditional informative health material. Similarities and differences between narrative messages regarding organ transplantation are seen comparing two different genres: a mythological tale, as shown in the story of Icarus and Daedalus, and contemporary transplant patient testimonial.

Keywords: Narratives, storytelling, health literacy, organ donation.

Introduction
Health literacy represents the skills of people to access health information, understand, evaluate it, make appropriate health decisions, and promote health [1]. Storytelling is an essential part of human nature, of the ‘Homo Narrans’, as is the need to communicate health information in an engaging way [2]. Narration of personal stories of patients, patients’ families, and healthcare personnel provide insightful information on how people experience health issues. Narratives, along with information based on evidence, such as facts and statistics promote health literacy, by enabling people to access health-related information, and personally process it, in order to better inform their decisions.

Narratives ‘reflect culture’ [3], and show perspectives, sometimes different from our own [4]. In medical education they can help students explore patients’ views and adopt a holistic perspective [5]. In the healthcare context, they inform, engage, provide models of health behavior and promote risk perception or severity of health conditions [6; 7]. ‘Existentially important experience’ is communicated through them [8] and the reflection that comes with it can be beneficial both to the storyteller and the listener [3; 9].

Narratives are stories, which can take many forms and be delivered through various means, such as testimonials, documentaries, conversations, either told by patients, healthcare professionals, or enacted by actors [10]. Trying to find the thread that runs through narration across time, we revisit a tale of Greek mythology and a contemporary patient story and describe ways of communicating information. For this we will use a taxonomy [11], which focuses on the three dimensions of purpose, content, and tone.

The tale of Daedalus and Icarus
Since ancient times storytelling and specifically through oral tradition, has been a common way of informing and engaging people, especially at times when most of population were illiterate. One tale which passed on through centuries and recorded in Ovid’s poem Metamorphoses (Transformations) [12] is the story of Icarus and Daedalus. Daedalus was an inventor and architect of the labyrinth in Crete and, along with his son Icarus, was a prisoner by King Minos in the island. Their escape plan was to devise wings of wax and fly to their freedom. However, Icarus flew too close to the Sun. His wax wings melted and Icarus fell. Their punishment came because the prince of Athens, Theseus, managed to exit the labyrinth after killing Minotaur, a creature with the head of a
bull and the body of a man, to whose honour each year young Athenians were sacrificed. Theseus had learnt the secret way out of the labyrinth, which only Daedalus knew, through Minos’ daughter [13].

This story has been interpreted as an allegory in an educational, social, and political context [14], portraying the fall of man as a punishment for his hubris; creativity and revolutionary inventions which overcame tradition. Revisiting this story within a health frame, there are messages relating to health literacy. This ‘science fiction’ story is a vision of transplanting animal organs to humans, a metaphor for xenotransplantation [15], which in the case of Daedalus is successful and saves his life, while on the other hand, it costs Icarus’ life because of a thermolabile adhesive leading to acute graft rejection, if explained in transplant terms [16].

The ‘xenotransplantation’ takes place, as Daedalus “fashioned quills and feathers in due order — deftly formed from small to large, as any rustic pipe from straws unequal slants. He bound with thread the middle feathers, and the lower fixed with pilly wax; till so, in gentle curves arranged, he bent them to the shape of birds.”

The purpose of this story is not to inform about facts or add knowledge to what people already know. Rather its purpose lies in engaging people by invoking their imagination, inspiring them to look beyond the limitations of the human body. It uses everyday words and images, familiar to all, to help the people understand the idea and its ‘technical’ sides and it also uses the feature of a journey undertaken by a father and a son, to add an emotional tone.

The bold experiment was dangerous and Daedalus warned Icarus: “My son, I caution you to keep the middle way, for if your pinions dip too low the waters may impede your flight; and if they soar too high the sun may scorch them. Fly midway. Gaze not at the boundless sky, far Ursa Major and Bootes next. Nor on Orion with his flashing brand, but way, for if your pinions dip too low the waters may impede your flight.”

The content of the message focuses on the physical outcomes and detrimental consequences of non-compliance to rules. Icarus, carried away by his arrogance and vanity, according to Ovid, forgot the precautions, “as he neared the scorching sun, its heat softened the fragrant wax that held his plumes; and heat increasing melted the soft wax — he waved his naked arms instead of wings, with no more feathers to sustain his flight.”

The evaluative valence of the story flows between positive and negative, high and low emotional situations, making the experiences of the heroes more dramatic. On one hand, the positive role model of Daedalus is presented, who has understood the process, had been active throughout the whole endeavor in working out the solution, and survives, as he complies with rules. On the other hand, Icarus serves as an exemplary case of what one should be warned of: disobedience and low self-management cost him his life.

Real life story

The second is a patient’s story of waiting for a transplant, as accessed at the NHS organ donation website [17]. On the NHS organ donation website there are three types of real life stories: of patients waiting for a transplant, patients who have had a transplant, and families who have donated their loved one’s organs. All of the stories contain a photograph of the patient or donor and a narrative presenting briefly the name and organ failure a person experiences, the course of waiting for a transplant, and then in the person’s own words the experience of a transplant.

The story of Simon is under the section of patients waiting for a transplant and it consists of facts about Simon’s health condition, organ donation and Simon’s feelings and thoughts about the situation he faces. It is a story whose intention is to inform about cases such as Simon’s through illustrating the impact on his life by having Simon’s consent to use a camera to record a typical day in his life- and use facts from his case to introduce people to the meaning of various aspects of organ donation, such as living donation, dialysis, and transplant waiting lists. It engages by using simple language to describe the logic of waiting lists ‘waiting for a transplant is not like waiting for anything else. You don’t necessarily get nearer to the top of the list the longer you’ve been on it. It depends on many factors including who is in greatest need and who is the best match for an organ’. At the same time, the narrative presents only the absolutely necessary statistics to show the demand of kidney transplants ‘5,000 people who are on the waiting list for a kidney. Over 450 of those people have already waited longer than 5 years’, thus not confusing the reader with further numbers and graphics, but only with those related to Simon, as he is in the waiting list for 6 years.

The content of the message focuses more on the experience, as it talks about the process of dialysis and what it has meant for Simon’s life, including ‘4 life-saving sessions of dialysis, indescribable fatigue and constant uncertainty for the future’ the expectations during dialysis “I’ve been on dialysis for 5 years. For me, it’s the most difficult part of the wait… I’m in limbo’ and the waiting list ‘My family and I are on a roller coaster, I can’t see the twists and turns or how it will end. It’s an endless wait with no ETA’.
The tone of Simon’s story moves along a continuum, with various gradations of uncertainty and hope. His story mentions the physical and psychological difficulties associated with the dialysis treatment, but sheds light more on the uncertainty both Simon and his family experience. This feeling is also accompanied by hope for a transplant that could ‘transform’ his and his family lives.

**Discussion**

Many differences lie between the stories discussed. A main difference is that Daedalus and Icarus’ story is a tale relying on fiction. It is an ancient ‘science fiction’ story, usually used as an explanation of how the Icarian Sea took its name by the fall of Icarus. It does not rely on facts or convey health-related information.

Yet, it conveys subtle messages which are in many ways applicable to a health context, such as compliance to medical instructions, patient’s responsibility for self-monitoring, patient engagement, support and follow-up.

On the other hand Simon’s story is a real story. It is a first-hand experience of a patient, who has already gone through a transplant, saw its impact on his life, and again faces new challenges, as he waits for a second transplant. It is a narrative about a personal journey, put within a more universal context of similar cases of people on waiting lists.

Both stories refer to existential issues. The former uses an allegory for showing the struggle to overcoming the body’s restrictions, whilst at the same time dealing with flooding emotions. Although Icarus does not start this journey alone, it turns out as mostly a lonely experience, missing the ongoing support of people who know more and interaction with others going through the same situation. The second story shows Simon as the main protagonist, who is, nonetheless, in a constant interaction with the medical community, and draws support from his family in various ways, from living donation, to sharing feelings and expectations.

Icarus’ tale has a didactic tone, which is meant as a lesson for all, irrespectively of their health. It tries to induce the fear of the consequences, when one does not comply with the given instructions. The message is clear cut, ‘one risks life, if does not do as being told,’ and portrays a fine line between success and failure, life and death. Simon’s story also shows consequences, through explaining words and giving them a personal, yet realistic meaning. The words ‘patient’ and ‘dialysis’ are explained not simply because the name of the disease is mentioned at the beginning of the narrative, but because he portrays his experience on dialysis. In the same way, ‘waiting list’ is explained not by medical definitions, but by describing how the list affects Simon.

**Conclusion**

From a health literacy perspective, Icarus’ tale shows that awareness and information on health issues and possible dangers are necessary, but not always sufficient to guide appropriate decision making. Cognitively, Icarus was provided with clear information and he had consented, having claimed that he understood it. Physically, he was prepared to meet the challenge, and he was aware of the procedure which was undertaken, and the materials used. However, emotionally he was unprepared for the ‘ride’ he had to go through, the stamina and other personal resources he had to use, in order to help his ‘body journey’, and failed to understand strategies to help him cope through, find out support mechanisms, acknowledge blocks to the endeavor, unlearn ways of thinking and doing, and replace them with more appropriate ones.

Simon’s story shows an informed and active patient, who is also engaged to become a link in the chain to raise public awareness. It puts a holistic perspective on this health issue, by showing Simon’s experience at a personal level, the role of the family, the health system, and the community. A health condition is not seen as a matter involving just the patient and a healthcare team. It is seen through the patient’s eyes, and how it can relate to people not immediately affected by it.

**References:**


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