

Inter-patient Narratives in the Internet

Abstract: The paper analyses the communication acts on inter-patient forums using the model of narrative chain (cf. Labov 2004). The term narrative chain usually denotes a partially ordered set of narrative events that share general features. The stories analyzed come from the patient forum of the Estonian Diabetes Association (www.diabetes.ee), established in 2004. The article presents the statistics of the popularity of discussion topics, and discusses how people are coping with the illness by sharing narratives, communicating and arguing, and what kind of narratives they use. I am going to analyze two distinct topics: 1) exchanging information regarding alternative medicine, 2) discussion about re-homing a diabetic cat.

Keywords: alternative medicine, communication, diabetes, computer-mediated communication, disease narrative, narrative chain, inter-patient narratives

Out of the 1.5 million people living in Estonia, approximately 70,000 are diabetics. In the whole world, more than 100 million people suffer from diabetes, the most prolific metabolic disorder. By the year 2010, the WHO foresees a doubling of the number of diabetics worldwide. Type I diabetics need several injections of insulin daily, they need to constantly keep track of their blood sugar levels and follow a regulated diet. Diabetics have difficulty finding work in rural areas, and they are not treated equally with their colleagues. Stereotypes say that diabetes causes bad temperament, moodiness and bouts of illness, making those who suffer from the disease poor employees. Socio-cultural models and common beliefs claim that whining and bouts of anger are an intrinsic part of the disease. Naturally, complications such as loss of vision and skin problems induce both compassion and

guilt, making the relationship, between the healthy and the afflicted, intricate. How do you explain to yourself the fact that you are healthy while your friend, through no fault of his own, suddenly develops a condition with unpredictable progress? Your friend, meanwhile, is battling strong emotions of his own and feeling very defiant. Step by step the new negative aspects come to light, for example, the need for self-discipline and an enforced regular, measured way of life. It is just as hard as the sudden realization that growing old is inevitable. One young person, finding out that she has diabetes, expressed her painful feelings, “:(:(I don’t want anything to happen to my beautiful nails, does diabetes mean that the whole body becomes ugly in time and health gets worse every day until at last you die?”

In human beings the emotional, psychological, spiritual and physical are inextricably linked, inevitably entailing provisionality, disturbance and lack of certainty. It is obvious that people are motivated to construct narratives centred on topics that help them deal with fundamental life issues, while sharing these narratives with others. Likewise, the philosophers Hermans and DiMaggio (2004) paid attention to the fact that some positions or voices in the self become exclusively important, and particularly in situations of anxiety and threat.

I have outlined the scope of diabetes since the sources for this paper comprise the Estonian diabetes online forum (www.diabetes.ee), established in April 2004. The narratives in the forum share personal experience stories of patients, and also common-sense beliefs, thematic argumentation, pieces of home-made philosophy, examples of figural speech in the context.

The paper will discuss how people are coping with the illness by sharing narratives, communicating and arguing, and what kind of narratives they use. I am going to analyze two distinct topics: 1) exchanging information regarding alternative medicine, and 2) discussion about re-homing a diabetic cat.

Method

The study is part of a project observing internet message board communication and narratives posted there. The stories analyzed here come from the patient forum of the Estonian Diabetes As-

sociation (www.diabetes.ee), established in 2004. All topics were spontaneous, not a response to outside provocation or a questionnaire. The discussed topics were posted in 2008–2009; the narrative chain connected with healer Viktor comes from 2005.

Research Setting

James W. Pennebaker and Janel D. Seagal (1999) have a very simple and clear scheme of how medical narratives are shaped:

Once a complex event is put into a story format, it is simplified. The mind doesn't need to work as hard to bring structure and meaning to it. As the story is told over and over again, it becomes shorter, with some of the finer detail gradually levelled. The information that is recalled in the story is that which is congruent with the story. Whereas the data (or raw experience) was initially used to create the story, once the story is fixed in the person's mind only story-relevant data is conjured up. Further, as time passes, we have the tendency to fill in gaps in our story to make the story more cohesive and complete.

In online forums, people do not post in a monologue but in an active multi-party interaction. Stories are not shaped as they are retold over multiple presentations, people present different episodes in different topics, and usually set stories and opinions.

An online message board represents different forms of communication: written communication using language close to oral speech. Every conversation is carried out between several people who take turns in posting. Posts are written with a time interval just like in e-mail correspondence. Replies are posted either at once or after some interval, sometimes even days later, just as the poster wishes. Participation in any given “conversation” topic is voluntary and depends entirely on personal interest and free will. Writing in direct communication, it is possible to participate in discussions, to engage someone in a dialogue, to express your opinion or attitude, confirm or deny some event, present a version of event or to introduce personal points of view or the whole world view.

The final result, a textual whole or written narration remains in the forum and can be returned to at any time, to be re-read, re-interpreted, or to continue the discussion some time later. It is a never-ending online book where you can add a story or chapter, years after the story was finished. The reader needs to reconstruct the dialogue based on the flow of the text (or posted texts), to interpret the event and to make a decision on the matter. For example, the narrative researcher Manfred Jahn asserts that, in the context of cognitive orientation, both the narrators and characters are deictic centres representing their gender and holding opinions and they are sources of rhetoric as well as situative entities guided by affect, purpose, motives and intentions. In order to understand a described phenomenon and to share in the narrative experience, the reader needs to project herself into a pragmatic identity (Jahn 2000).

In the case of written online texts, in order to make decisions about the reliability of a character or narrator, readers attribute to them “a certain psychological identity, categorizing them into socio-cognitive types like liars, cheaters, exaggerators, neurotics, lunatics, etc. (Jahn 2000).

To characterize narrating on the forum of diabetics, I used the term “natural narratology” which was proposed by Monika Fludernik in 1996. Fludernik applied her theory to postmodern literature, pointing out that the text flows in there are interchangeably similar to communication during an act of social interaction. This was what lead her to experiment with the reverse – narrativity on a certain internet site where the text flow was supposedly reflecting real life information and living. Since Fludernik emphasizes that in narrativity parts/stories with and without a plot are equally common (Fludernik 1996: 235), the model is well suited for the analysis of the narrativity of internet communication.

Fludernik (1996, chap. 1.3) stresses the importance of the cognitive frames and structures, especially experience plans, narrating and echoing of the real world, as theoretical units. According to her, there are prototype narrative situations in any given conversation/communication style of narration, acting as the default framework for concepts like narrative communication, story and discourse, narrators and focusers, pragmatic agreements, good traditions, good performance, etc. Another

model, well suited to analyzing written text produced by forum interactions, is the scheme of William Labov. There are times when the written discussion is similar to narrating strategies used in oral conversations, making up narrative chains (Labov 2004). The majority of stories told in the community are short pieces of everyday conversation. These acts of communication are a narrative chain of socio-cultural acts of speech, where different personal communication and narration styles as well as personal identities meet. In that case texts are in complexity, but we as readers can divide a text into ambiguous and unambiguous regions.

The term narrative chain has been used in several connotations. Usually it denotes a partially ordered set of narrative events that share a common actor, the protagonist. A narrative event is a tuple of an event and its participants, represented as typed dependencies (Chambers & Jurafsky 2008). However, on an internet message board it is a chain made up of arguments and narratives told by different voices. For example, William Labov used a narrative chain since “any given narrative is constructed about a most reportable event: that is, an event that is the least common and has the largest consequences for the welfare and well-being of the participants. It is also a product of the inverse relationship of reportability and credibility. A recursive rule of narrative construction produces a narrative chain, a skeleton of events linked by their causal relations” (Labov 2004) but also in the meaning “reportable events united with unreportable events into the chain” (Labov 2007). Beside the main storyline (or several main storylines), people converse on topics (only slightly) related to the main topic, giving different comments, arguments and counter-arguments without the opinions forcing any one party to take any of the suggested courses of action. In this kind of a narrative chain, units without a plot (sentences expressing opinions, beliefs) have their specific role and function.

Communication is sometimes initiated by an announcement about, or question for, a solution to a specific situation. For example, whether to tell the teacher of the child’s diabetes, how to keep blood sugar within norms, etc. Questions for advice are usually replied to with suggestions and experience narratives. These posts and simple informative life story fragments open

different personality types to us (some cannot take informing about the disease, other see a positive side to this and their special status, and yet others remark on the changing attitudes and diffusion of knowledge in society).

Results. Overview

In my previous article (Kõiva 2009) I analyzed doctor-patient communication and communicative chain narratives in patient communication. The doctor and the patient use different cognitive models and represent not equal but different socio-political interests (cf. Kleinman 1980; Singer & Baer 1995: 375). The patient is the subordinate with a lower position. However, the environment where communication takes place gives rise to specific choices in language usage, structure and length of a communication act, its level of complexity and use of different styles. Change of communication codes is determined by the motivation of the partners as well as perception of the setting's nature. If a patient is looking for help from a representative of the medical profession on an institutional page, the communication codes and language are formal and polite, with a serious matter-of-fact tone. Word choice indicates that the patient is aware of the severity of the situation and his position. Communication on doctor-patient forums is characterized by a definite beginning, central point and ending (cf. Thornborrow & Coates 2005: 7; Kõiva 2009), a short and clear structure common to classical narratives.

Communication on patient-patient forums is wider in the range of styles and topics, closer to how an offline interest group interacts. When the diabetes forum had just started, questions were posed and discussions initiated by family members, relatives, friends, but soon the environment were dominated by communication between the afflicted. There are periodic announcements posted by the co-ordinator of the Diabetes Association, mostly concerning changes in laws and social benefits.

The virtual community has a stable core member group and a flow of members coming and going, as they get older or migrate and their life changes. When the forum started in 2004, there were many anonymous posts. In the first years there were also

many questions from and discussions participated in by family members and relatives of the afflicted. After some time, they disappeared and the forum members' active majority became the diabetics.

Typically to all open web communities, the number of readers, lurkers, stalkers, observers vastly exceeds the actual posters. Smaller threads are read on 350 occasions, while popular ones are read thousands of times. The passive portion of the community is so much bigger. The bridging person is the official head of the association, who is not actively involved in discussions but whose announcements are always read.

People afflicted with a difficult or fatal disease find moral and mental support from people in similar circumstances participating in online forums. They get help evaluating the state of their health, they can exchange experiences with the progress of the disease (whether for the worse or for the better), share their coping strategies, and act as experts. There are important motivating factors contributing to patient forum interaction: interacting in a community, receiving objective evaluation on treatment, gathering information about the disease and treatments, the opportunity to just talk about the disease, hopes for alternate and effective cures. Web discussions tend to branch and include in addition to rationally explained suggestions also advice based on personal experience.

Popular Topics

Lorne L. Dawson emphasizes the connections between the internet and ordinary life:

For individuals, life online must be placed in the context of life offline. Life online is largely continuity with life offline and must be examined with that relationship in mind (Dawson 2006: 33).

The posts in the diabetes forum indicate that the communication in the forum is primarily related to health and the disease. Naturally, people also write on other topics, yet the issues concerning diabetes remain as the dominant theme. Indeed, this fact is undoubtedly conditioned by the environment – this is the official forum of the Estonian Diabetes Association which simul-

Fig. 1. Posts

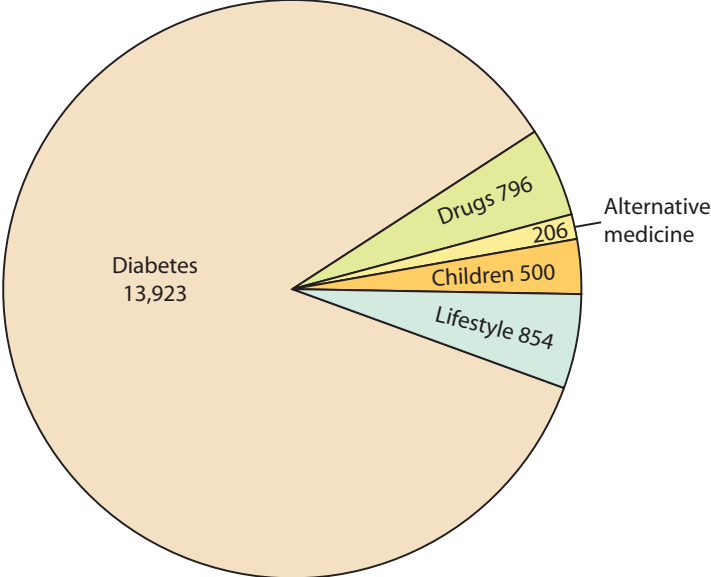


Fig. 2. Viewing

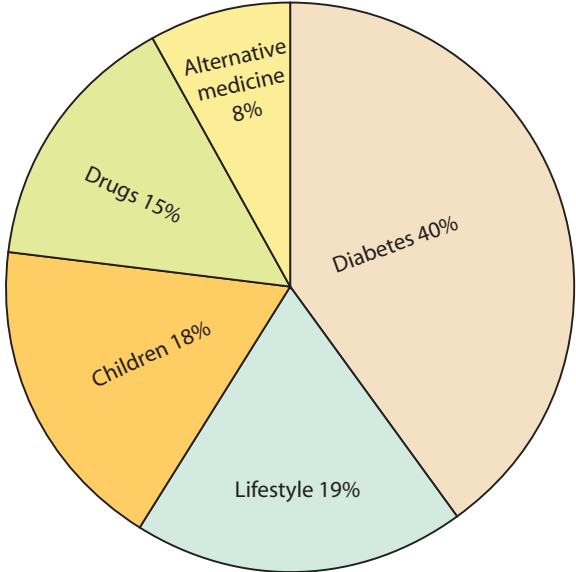


Fig. 3. Popular topics

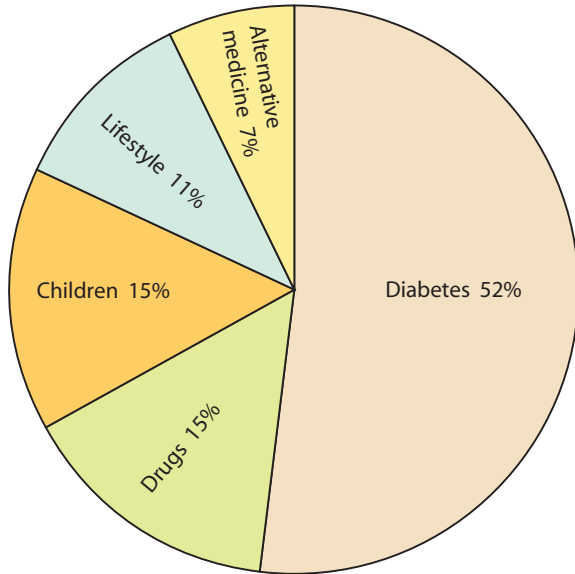


Fig. 1–3. The most popular posts, viewings, topics.

taneously directs and motivates the topics for the participants in the forum. Forum members value their community interaction space as a practical forum where people report on their disease experience, and more importantly, relay information on their empirical experiments with drugs and keeping diabetes under control.

The number of single posts during an episode is, on the diabetes forum, from one to more than three hundred. The number of views a thread has received is more than ten times of that. What is it that connects stories with such different amounts of posts? According to Monika Fludernik, narrative is related from a human experienter:

In my model there can be narratives without plot, but there cannot be any narratives without a human (anthropomorphic) experienter of some sort at some narrative level (Fludernik 1996: 9).

International studies of various affliction-based forums indicate that the group has a positive influence on the individual participating. The most important factors are considered to be exchanging information, encountering emotional support, finding recognition, sharing experiences, helping others, and amusement. Empowering outcomes included being better informed; feeling confident in the relationship with their physician, their treatment, and their social environment; improved acceptance of the disease; increased optimism and control; enhanced self-esteem and social well-being; and collective action (Uden-Kraan, Drossaert, Taal *et al.* 2008).

The following statistics concern posts made in the year 2009 (1st half) that have been viewed more than a thousand times. During 2009, participants discussed 194 different topics. Having a look at the popularity of discussion topics confirms that the generalization is appropriate. The most read and discussed topics are, indeed, about drugs, discounts, the future of children and other daily concerns related to diabetes. The most popular topic was diabetes (28 topics, 13,923 posts: 95,102 viewings), central issues include the progress of the disease and its complications. I introduce only four of the most highly viewed problems: combinations of thyroid problems and diabetes (37 postings and 10,467 viewings), discount test strips (121: 9,191), nails and fungi (44: 8,208), high blood sugar (24: 5,789).

A central topic is also drugs as well as drug suggestions (8 topics, 796 posts: 35,923 viewings), for example Insulin (287: 7,098). A popular topic of reading was alternative medicine and the methods it employs. Herbal remedies (including herbal teas) can be helpful in the early stages. Although there were only 4 topics and 206 posts, it had 19,762 viewings. The most popular was the healer Viktor (more than 8,400 viewings), but we must mention that the main discussion took place as early as 2005.

Healthy children, the diabetic child in kindergarten, getting a disability paper for the child, pregnancy and diabetes are topics that lead to generalizations like: the probability of having healthy children is 2–10%. All diabetic children go to regular schools and kindergartens. The first year of diabetes is spent on learning about the disease and getting used to it. During 2009 there were 8 topics, posts, and 43,188 viewings.

An even more important one is youth lifestyle questions – to fit in, to wear studs in the nose, lips, eyebrows. Only 6 topics with 854 posts: 46,598 viewings. For example, the belly-button ring topic had 470 posts: 21,471 viewings. Of course there are everyday topics or some special cases like cats and diabetes (68: 1,864), something nice for the Christmas table (11: 1,510) and different get-together meetings (17: 4,000).

Over the years, the most popular topics are largely the same, as well as during the second part of 2009 the number of readers, of the most popular topics, grow.

Case Studies

It is clear that some topics enable the exchange of specific brief information which is rarely developed into a personal experience narrative, whereas other themes connect the varied-length narratives by way of narrating strategies. The majority of stories told in the community are short pieces on everyday life or short accounts of events. The so-called little narratives are informative short stories that carry and contain goals and symbols important for the community. Typically they have no strong structure, nor specific wider value, they are small pieces, narratives which are very important to the persons or their family or friends but not for public auditory.

The conversation can start from someone posting a personal experience narrative. These kinds of posts form up to a third of those posted every year. Often a single person starts only one (a max of 14) such thread all in all. The second type is where an anonymous question of wide scope is posed. The anonymity of the thread beginning seems to be used as an indicator that responses from all and any are welcome, and such threads quickly attract hundreds of responses.

In many cases, communication takes place as a dialogue between several people simultaneously communicating, answering and replying in turns, now and then offering expert opinions, vying for attention or trying to push one's personal point of view. Similarly to oral speech, the narrative as an integrity takes shape in the course of a longer communication, wherein details are being specified or confirmed. Situation descriptions

are interspersed with humour and metaphoric expressions. These acts of communication are a narrative chain of socio-cultural acts of speech, where different personal communication and narration styles as well as personal identities meet.

In the following, I will take a closer look at three cases. The first chain narrative is the topic of alternative medicine, with the largest number of readers, concerning those who have been to healer Viktor to be cured. While selecting alternative medicine for observation, I proceeded from the fact that people, when combating their disease, are ready to use all means and try even those medicinal products they would never even consider in case of a more lenient disease. This is particularly true in a situation where a child is inflicted with a disease and all opportunities are seized to combat the disease. Likewise, this topic involves folkloric and generally common motifs, attitudes and beliefs, the ones I have studied as a folklorist by way of interviews. The conversation in a web environment takes place in an atmosphere that is much more typical to a spontaneous conversation, without the disturbing factor of the researcher.

In the current phase of research, however, it is difficult to say how many people have visited alternative medics or healers. Pursuant to an intuitive estimation, one fifth of all families have probably utilised such possibilities, at least for consulting, or obtained relevant information from their acquaintances. Still, there are no elaborate studies regarding the actual choices of patients as there is a significant distinction between an intent and action. Approximation of the treatment methods of official medical care to biological cure, and the recommending of medicinal plants as an option would probably facilitate the search of other similar opportunities in an urbanised environment.

The second chain narrative has been selected as an example of expressing emotions and conveying information by way of experience narratives.

1. Case of Wonder Healer Viktor – Narrative Chain From 2005

I am going to next present, as an example, a concentrated discussion about an alternative medic. The healer Viktor (Viktor

Tõnissoo, 1931–2010) has been active as a vernacular doctor since the 1980s; he has been widely discussed in the media. His specialty relates to pictures that heal and he has sold them during the last 30 years. According to beliefs, the pictures helped against different diseases, whereas the fading or tarnishing of the colours would forecast a disease to the owner of the picture. He has a wide range of patients and many people have had contact with him. During 2001 Viktor was an official media hero – in the interviews he recounted finding a successful drug against AIDS. The next bigger media event happened in 2006, when a cancer patient, a 61-year-old lecturer of Pärnu College recited his pathography, which consisted also of treatment by Viktor.

The following discussion forms a cohesive narrative whole, with personal experiences and narrative insertions from various parties. The initiator is the story of a kid's father's visit to the healer Viktor, with the mother asking others their opinion of whether the visit had any point at all. The chain narrative is centred around one person, and to some extent also one story – after people have said all kinds of things about Viktor and treating in general, she presents her daughter's description of the visit, making Viktor out to be a cheater. At least that is the way the mother presents the story. The mother is also worried that people still visit Viktor – he is obviously a fraud, but there is something that does not let the desperately hopeful comprehend this. Out of the 67 posted letters, 40 posts are associated with the first episode. By way of applying the scarce web resources, the mother's letters skilfully convey emotions and hesitations.

01.02.2005 15:25

The father of my kid took the kid to the healer Viktor (in Tallinn) and he had prescribed some kind of medicine (produced by him). I really would not like to give this to the kid just so... has anyone heard anything about healer Viktor??? He's said to be world famous???

This post is followed by a communal discussion of preferring folk healers versus medical doctors, belief versus trust, informative messages and expressive evaluations on relations between diabetics and folk healers, as well as stories of specific folk healers.

The discussion stretched over eight days. We see a predominant discourse of didactic warning and preference/trust of the regular medical system.

Angry anonymous, 01.02.2005 15:56

I don't want to take away anyone's hopes, but if someone has heard of a healer that could bring back the dead[,] and knows of an actual case where someone has been brought back from the dead, that bonesaw I'd try myself too... But since that (bringing the dead to life) is obviously impossible, there's no point trying [them]. A type II diabetic could try all this rubbish. Those who promise to heal type I diabetes don't know nothing about diabetes at all and similarly do those that take their kids to such healers.

01.02.2005 16:02 Mother

I guess he didn't really promise to heal fully but to make the state better??? And also seems to have said that thyroid readings are not quite well either. But, well, I don't know, I would not like to believe him.

The following posts give additional details about Viktor's actions, together with the poster's personal opinion. The doubtful evaluation and conclusion with a negative subtext naturally they praise the effects of their "medicines" is followed by a shorter (principally true to the rumour or urban legend model) positive note about how the father of a friend had help in arresting cancer.

01.02.2005 18:07

Hello,

I don't know if it's the same so-called healer, but I have heard of someone of the same name for years. Once he offered the easily impressed some kind of "miracle pictures" that you look at and then your physical troubles are eased. Can't really comment on the success rate of such healing methods, but I dare doubt a positive result. In any case, those miracle doctors should not be trusted. But naturally they praise the effects of their "medicines" and "healing methods", because otherwise nobody would come to them and where would they get money from then.

Mirka

01.02.2005 20:54

hello. also something positive. he did help the father of one of my friends. that man was written off by the doctors. he was cut open and they said there's nothing to do, a tumour in the liver. that viktor instructed what and how to do, and unbelievably he got well and lived another 5 years but then died of high blood sugar.

The following stern admonition, according to netiquette delivered by shouting, is based on the personal experience of a diabetic, the childhood memory of how the disease was tackled by a folk healer, leading to a remission, as expected. This post, therefore, supports rational medical efforts and ends with the reminder that the situation is not the worst possible so long as rational behaviour is applied.

02.02.2005 15:30

i would never dare give some kind of x stuff to my kid. i have been diabetic since childhood and my parents also took me to some healer. he also gave some kind of medicine, i took it a few times and then refused, the parents forced me, i didn't take it. it all ended in hospital. PLEASE, DO NOT HARM YOUR KID WITH SOME KIND OF STUFFS – GO TO THE ENDOCRINOLOGIST – THEY ALSO CHECK THE THYROID GLAND. I can understand that this gives you hope, but your kid is far from dying. help him with self-control and be supportive. ALL THE BEST TO YOU! KAKUKE.

Negative personal experience with folk healers and corresponding advice is presented also in a post made two days later.

04.02.2005 08:51

I advise not to undertake such things. If diabetes is being compensated, blood sugar is fine with temporary and natural fluctuation - then the situation is good. I have experience with various healers and one thing is for sure: none of them know anything about diabetes or any other chronic (or maybe simply any) diseases. Even many real doctors have strange beliefs about diabetes, what do you expect of "healers". He probably inserted thyroid problems to make it sound more serious, the more troubles – the more profit. Those wannabes are shameless people.

The initiator of the thread, the mother asking for advice, culminates the discussion with a description of the healing ritual she received from her child. This helps her solidify her already negative opinion of the healer.

08.02.2005 08:25

Yes, that "medicine" I sent back.

Thanks to all who answered. I thought the same myself that it's not worth the trouble (but, well, the kid's father was all full of power and belief).

It was very interesting what the kid was telling me yesterday... that when they were with father still at the reception then the healer had said that right now blood sugar is around 20 but he's going to take it lower right away... then he wrote something on the paper and said that now it's 4... the kid then said, oh great, I'll go home and measure it right away.. then the healer was like taken aback and asked where do you live... the kid then told him (around 2 km)... then the "healer" said that this is such a "long" way.. by that time it might be higher again... LOL!!!.. Pity the kid did not describe that incident before, I'd have known right away what to do.

Then follow shorter (disparaging) comments from fellow forum members. The discrete line of the narrative episode brings forth different cognitive approaches, narrativity, argumentation and experience. All in all, it is quite similar to oral dialogue between several parties. In both cases we are dealing with a communication act that allows a multitude of opinions, and during which concessions are made and judgment on the situation is offered.

Personal experience forms the basis of all stories. Many stories include warnings and behaviour instructions based on the poster's experience. Similarly to oral folk narratives, there are no long detailed descriptions of people, places or actions. Time-wise, the stories come from the childhood of the poster, from years ago, and less often from recent past. Viktor as a healer is discussed again about a week later, from another angle, and once again a month later, but then interest wanes within a few days. In the following posts we can see a lot of humorous joking, but also fending answers and irony towards naive questions and descriptions.

Evening.

Interesting, that if that Viktor does bring dead cells back to life, like he claims, then restoring one clouded eye should be piece of cake for him.

Blind boy from Tartu

Well if you are going to have anything done, have both eyes repaired.

Sceptic

Is this the same Viktor that I know?

I know that I have gotten help – he removed a curse that my own mother had laid on me. Many of the symptoms of the disease disappeared. I have waited for a long time to get Viktor's contacts. I did not visit him myself – a good friend of mine did, and Viktor also extended his life because the doctors could not understand how it was possible to live so long with such a difficult heart condition!!!

Do you think Viktor could also help with lymph cancer?

Angry

26.07.2005 08:18

Oh, well, he dangles the pendulum and heals all known and unknown diseases with it, wakes the dead back to life and makes other works of wonder....

Anonymous

Also later, in 2006, 2007, 2008 different people describe their experiences with visiting Viktor, ask for his contacts. There are long discussions about alternative medicine where the active forum member Skeptik explains why a miracle doctor can not help a diabetic and which are the main hoodwinking schemes. In 2008, a similar discussion with a narrative core emerges when a forum member describes how he sought treatment and then agreed with Viktor on a home visit that did not happen. The purpose of the home visit was to test the miracle healer's powers. After some admonitions on the forum, the poster expresses his regret since he is informed that Viktor had been hospitalized at the time.

The briefness of the following episodes is probably caused by lack of an intriguing real life episode or narrative that would inspire emotional discussion. Unlike in posts on a doctor-patient forum, here we can observe emotional and personal styles, taking advantage of all the means the internet as a medium provides. This is why we see interpunctuation used for pauses, all caps for a loud or insistent declamation, short-hand abbreviations for paraverbal acts (LOL – laughing out loud). Besides full-length stories and episodes there are also free-form discussions and arguments. The whole discussion is made up of the speech acts of different participants, narratives and narrative-like texts, statements, affirmations, denials, which the later reader will conceive as a full conversation. When we read a personal experience story and the surrounding discussions after the thread was finished, we do not perceive the time lapses or bumps in the flow of narration as the whole was built up over days. Therefore, a story is divided between two realities: a communication process moving from densely to loosely occurring acts of narration and communication, and secondly, an authored readable story. A case as it is read in retrospect is more compact than the communication producing the texts as it took place in real life.

2. The Diabetic Cat Samuel

Storytelling and narratives make emotions visible, just as Mattingly and Garro (2000: 11) have indicated in their analysis of medical texts. Verbalised emotions are echoed in many experience stories, from those about finding out about being diabetic to those of finding out about their child's diabetes to those describing the progress of the affliction. A topic read and emoted to do not mean a solved problem – this is the generalization we can make based on the topic of re-homing the diabetic cat Samuel.

One of the most read topics in 2008 was the search for a new home for a diabetic cat called Samuel. After visiting the cat in its foster home, one of the forum members decides to find the diabetic cat a home. The communication thread starts with a personal experience story where the cat, its habits and treatment scheme are introduced:

Me and my sister visited cats in a foster home and noticed that one of the cats was separate, in a cage. It came out that the cat had diabetes and therefore he needs special food and can not eat cat food the others have, and the others should not eat his food (they would gobble his special diet food). The cat was otherwise VERY friendly, no exaggeration here, just looking at him made he starts purring.

The forest home people said that this cat does not want to be stroked or strongly massaged :D. I stuck my fingers through the cage wires, and he at once settled so that he would be scratched behind the ears and under the chin. :)

The cat is young (2–3 years), male (as you can tell by the name), big sized striped hunk. Found on Öismäe Street, behaviour indicates that he has been a pet thrown on the street. Neutered/vaccinated. According to the doctor, he has not been ill for long, his organs' work has been analysed – his health is currently very good, no complications.

In a word, the point of my story is that maybe one of you would be willing to adopt this cat – a cat like any other cat, but with a small quirk which we can so much better understand than the rest of people. As you know, diabetes is nothing to pity or fear, injecting is not torturing, the cat does not need to be starved, he is not about to “die” or “collapse” any moment, etc. The foster people mentioned that if it were not for diabetes, such a friendly cat would have found a home long ago.

NB! For obvious reasons, this cat must be an indoor-only cat that can not be let outside alone.

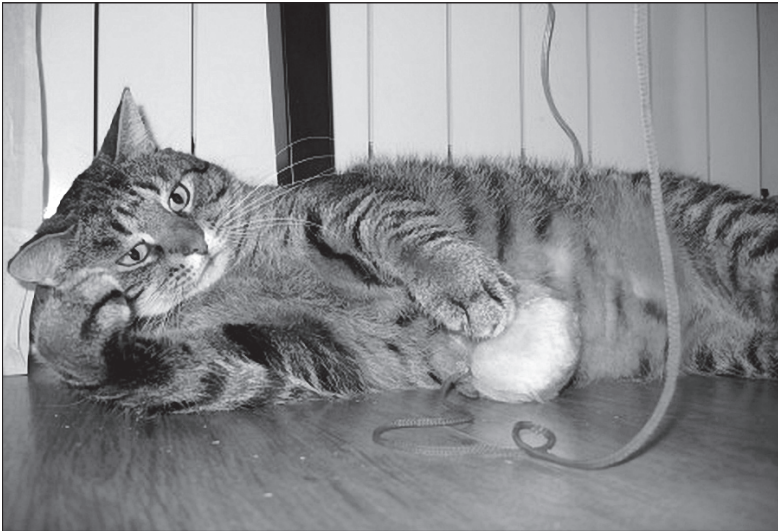
If you can not adopt him but would like to help, and then just spread the word, maybe it will reach the right ears and the cat will get a new home :)

Finally, the poster decided to draw a picture of what would be the detailed budget of keeping a cat, without the expenses of diabetes. The sum is startlingly big, surprising even for the poster. Then a long letter overviewing diabetes in cats follows, more examples of the cat's especially sweet nature and a note that the expenses are actually not so big – only food and litter, the basics:

The doctors say that there is no scientific explanation but for some reason the cat is the only animal that can get well of diabetes. Because of his really great character, Samuel instantly became a favourite of the doctors.

The author obviously made a great communication mistake: she does not talk about the time, energy or financial responsibility towards an afflicted cat, but instead concentrates on the generic expenses of keeping a cat. There is also a lot of emphasis on the cat's truly fabulous character, but not the price of meds, special care, etc. Those aspects are highlighted only by the forum in the ensuing discussion.

The replies on the forum are hesitant and making excuses. People want to comment on the topic, but for different reasons, nobody is willing to take the cat: already have pets, not willing to take an adult pet, partner forbidding taking pets, the expenses of a diabetic are high and two means double the expenses, and forum members who have diabetic pets describe their maintenance. The replies often invoke empathic posters to tell their own story.



Many high-spirited portraits of the diabetic cat Samuel were put on the web. "Maybe I should play a little," Samuel seems to be thinking.

Already when I read the first post about Samuel I felt the need to say something but I didn't know what to say and I still don't have anything sensible to say.

I am very sorry, because the illness of a pet is almost the same as a child's when the pet is a member of your family. And animals are loved in our family. We have long debated taking a cat and dog for Pauline since she is crazy about them and we wanted to take the cat and dog simultaneously so they would be used to each other.
[---]

This does sound like an excuse but reading all those posts it did make me feel kind of guilty...

As the conversation progresses, the initial poster reveals her motives – she is a diabetic and already owner of several animals, and it would seem rational that a diabetic cat would live with a diabetic human.

If anyone is interested why I am not taking the cat myself, I already have 2 cats and a dog and you need to draw the line somewhere.

Also, the argument that a child will get used to injections seeing the pet injected does not sound plausible. There are also much more rational arguments:

I would not make excuses but would explain the matter from another aspect. A couple of my friends have a dog with diabetes and you know, another thing is that animal diabetes seems to take as much money as human diabetes since there is probably no discount for veterinary insulin? We have discussed here the general topic that many spend a significant amount on strips and needles, which means that paying full-time for the pet's medical needs may be too much. It's just that it would be nice if the kitty found a quite healthy person who feels the need to take care of this animal. I really do hope you find this owner! We have a cat, a dear member of the family and a favourite of the children. Therefore I can very well understand what kind of animal a cat is and a how lovely they are, even with a small health problem (although diabetes is in fact no small health problem).



Diabetic cat Samuel finally got a new home. Photo by V. Nieminen, 2009.

As the year progresses, people inquire about the cat, they remember the topic, but there is no solution. In October, the cat is still homeless.

Hasn't Sam found a home yet? I discovered this topic and told my husband about it, too. He would not want a cat at all, he wants a dog. :D But if Sam is still looking for a home I could try persuading my husband. :D

At least as a “temporary” home... If that is acceptable, of course...

Conclusion

One member of the diabetes forum reminds the others that diabetes is not a disease but a lifestyle. The profound generalization reveals the philosophical and truly important aspect in the discourse of illness and health that is often not consciously considered. The examples provided here make up a negligent part of narratives on the forum. The discussion groups are used as a replacement for the role once played by the extended family or local community – discussing illness and health and looking for solutions in the discourse. Since post-modern lifestyle and interpretations accept a different set of knowledge, and are largely oriented to subjectivity – the multitude of opinions expressed in an online discussion group conforms well to the modern style. Important goals for narrating are:

- Exchange of trauma of disease experience narratives
- Diagnosing the current state of health
- Exchange of experience on drugs and alleviating strategies
- Coping strategies
- Exchanging expert opinions and enjoying the status of an expert

People afflicted with a difficult or fatal disease find moral and mental support from similarly affected people participating in online forums. They get help with evaluating the state of their health, they can exchange experiences about the progress of the disease (whether for the better or for the worse), and share their coping strategies. Similarly, so-called writing therapy is gaining ever more ground with the seriously ill. The online communities can be seen as a spontaneous branch of the same. Online environments oriented to uniting disease-specific groups have several advantages in this respect, in fact. They offer the opportunity for dialogue with people in a similar situation. At the same time, it is possible to maintain privacy and anonymity.

Since interaction on the forum is close to natural oral interaction, we can use this to study narration and narratives that are hard to catch in oral telling. Communication in patient forums is based on information, the shared disease experience and narratives and they play an important role in maintaining mental balance. Besides short narratives that carry information and important symbols and messages, there are also joking, mocking or didactic stories and social interaction threads, adding up to a didactic whole. Attractive real-life events give rise to longer communication situations. Reading archived descriptions of the disease, one can provide an auto-diagnosis; get an overview of the progress of the disease, the symptoms, relapses and possible treatments.

Forums provide impressive possibilities to demonstrate emotions, and the role of emotions in everyday life. Also it is remarkable how often a discussion is based on personal experience and narration of personal life episodes as the model and example for solving a problem. This is perhaps a very promising evidence that benefitting from writing is linked to forming a story about one's experiences. Similarly to oral communication, a narrative chain is made up of parts of different genre and styles, of parts with and without motifs.

In discussion, we see clashing opinions, just as in oral conversation: people represent different positions, defend their views and present them for acceptance, present counterarguments; they are the authors of their narratives and the carriers of their identity. The forums contain many examples of generalizing and common philosophy, often as an inseparable part of a narrative. One discussion is summarised by someone who was helped by a folk healer:

I think that everyone has the right to choose between alternative and regular medicine. These two branches should work hand in hand, like elsewhere in the world. First of all you need a positive attitude toward life, which those having to deal with the regular medical system find hard to maintain. Many do not have progressed states of the disease and cold really use a positive charge. The matter is more in the person's mind, beliefs and goodwill. [---]

James W. Pennebaker and Janel D. Seagal (2006: 1252) formulate that neither of the personalities variables of the author, nor qualities of the audience to whom the writing is directed matters in predicting benefits. An analysis of the writings that people produce has revealed copious use of positive-emotion words, a moderate use of negative-emotion words, and an increase in the use of insight and causal words.

The online community of diabetics follows the model of real society in its division of roles, activity, etc. Characteristically of internet communication, in addition to real-time interaction and narrating, even carried out in continuity-interrupted intervals, an important result is that the entire communication episode is recorded as a unit that can be reviewed at any time. In this manner, forums produce information, narratives or texts that can be interpreted or used multiple times.

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Through the Ages II. Time, Space, and Eternity

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<http://www.folklore.ee/ri/pubte/ee/sator/sator13/>

ISSN 1406-2011 (print)

ISSN 1736-0323 (web)

ISBN 978-9949-490-98-1 (print)

ISBN 978-9949-490-99-8 (web)

Tartu 2015

Printed version: Mare Kõiva. **Through the Ages II.
Time, Space, and Eternity.** SATOR 13. Tartu 2014

Author: Mare Kõiva

Series editor: Mare Kõiva

Editor: Liisa Vesik

Translators: Liisa Vesik, Mall Leman, Lii Liin,
Tiina Mällo

Cover design: Lembit Karu

Designed by NGO Estonia Folklore Institute

HTML: Diana Kahre

Electronic version editing is supported by EKKM14-344
Expansion of the sphere of use and introduction of the
Estonian language, culture and folklore in electronic
information carriers.

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© 2015 Cover Lembit Karu