



On-line medicine.
Narratives in the Inter-patient
Discussion Group

ESF 6824

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Research grant

„Internet. Processes of construction, reproduction and transformation of narratives, values and identities”
my area of research has been on-line medicine and new religious on-line communities.

Communication strategies and key values characteristic of the community,
communication opportunities
narratives.

www.kliinik.ee and www.diabetes.ee which shares medical information and personal experience stories.

The most prolific metabolic disorder in the whole world.

Type I diabetics need several injections of insulin daily, they need to constantly keep track of their blood sugar levels and a strictly regulated diet.

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.

By the year 2010, WHO foresees a doubling of the number of diabetics.

Recent research has pointed to the erosion of community relations, growth of isolation, fragmentation and distancing from responsibility towards others. This also means a decrease in political, social and religious participation, voluntarism and among other things that 90% of adult social relations are connected with their workplace (Putnam 2000, also Shklovski & Kraut & Rainie 2004).

In connection with this, the question arises whether internet communities follow the same trend or do they rather replace the former civil and family communities? Or, are they an example of transformed communication models?

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late 1990s development of e-medicine in Northern Europe and North America with funding from the national governments and the big medical corporations.

The large information management systems and support became a political issue.

Health information and advice online was a quickly widening internet service. 2005 opening of Estonian online advice centers.

Information portals manned by medics and directed to the layperson

a) provide complex e-service packages: give authorized information on specific medical problems, notify of new medicines and publications in the field, give advice on diet and food consumption; they also support the discussion groups.

b) consultations by psychologists and pharmacologists,

c) links to useful articles, interviews, health tests and topical discussions.

d) humorous corner and health texts - a set of entertainment and advice.

Questions and answers form a local archive and ultimately a large corpus of disease narratives.

Narrativity in the doctor-patient forum

Doctors and patients follow different cognitive models and represent not equal but different socio-political interests (cf Kleinman 1980; Singer & Baer 1995: 375).

language usage, the structure and length of a communication act, its level of complexity and use of different styles.

Patient: sufficient self-presentation is giving a first name and age, or a broader geographical region. The doctors, however, provide their full name, adding weight to the value of their expert judgment.

Structure

Patient: greeting, self-presentation, earlier case history, medicines used, question, thanks.

Doctor: greeting, an evaluation of the patient, case history, warning, suggestion to get further opinions / analyses, signature.

Katrin, cardiology 24.02.2008

High blood pressure

I am a woman 23 years old. I have had high blood pressure for about 8 years already (100–115/134–170). I have done all kinds of analyses (heart, kidneys). Everything seems to be in order. It is probably hereditary (my father has it, too). I am reluctant to take pills. I am aware about healthy lifestyles (sports, weight, nutrition, etc.), but they do not help lower blood pressure.

What could I do on my own to keep blood pressure within norms?

How long can the body take high blood pressure? How long before possible complications (clots in blood vessels, etc)?

Thanking you in advance Katrin

Reply: Märt Elmet 25.02.2008

Hello,

Such blood pressure values are too high, they must be reacted to.

You are much too young for hypertension and thus doctors should seriously look into what causes the high blood pressure. There are many possible causes and they are often hard to determine.

Hypertension begins its devastation at once. Finally the constant damage to organs reaches a critical level and causes serious health trouble. Unfortunately, the first complications of hypertension may be disabling or fatal (for instance, insult), thus the problem requires instant action.

Medicines can only be proscribed when analyses have determined the dysfunction in the organism.

Märt Elmet

Comment:

The poster uses formal language to pose the question. choice of words not used in oral speech but common in medical jargon.

The case history is also striving for accuracy.

Pretensions to objectivity in written narrative is close to the real-life patient-doctor dialogue, except here there is no dialogue development and the communication is limited to one exchange.

Communication provides guarantees about the **trustworthiness of the source** and the **level of professionalism** of the internet mediated communication. The main goal of communication is **to get objective expert opinions on treatment schemes or medicines used.**

Another important function is **testing how serious a problem is.** It is not rare that the doctor replies with - get analyses done quickly, dangerous, call the ambulance, or the like.

Honorable Mr. Ennet!

I would like to ask from You information whether there is an increased risk for depression among type I diabetics? I do not mean hereby additional stress from the additional burden or worry over health, but for example whether the constant fluctuations of blood sugar (inc. hypoglycemic) could cause serious disruption, on the so-called organic level, for example for serotonin or other "happiness hormones" and thus the risk for contracting depression? Looking forward to your reply, with best wishes.

Reply: Dr. Jüri O.-M. Ennet, psychiatrist and sports doctor,
private psychiatrist practitioner 2008-03-21 12:44

An organism is a whole, everything affects everything else. If we sit by with idle hands, then depression can really set in. Do psychoregulatory exercises and mood gets better.

Consequently - keep diabetes under the wise guidance of the endocrinologist and guide those hormones of happiness with by psychoregulation (begin with my exercise - Prayer-Meditation).

The whole world was created for us so that we would be happy. Thus use those objects-situations that make us happy, and do not use those that do not make us happier.

Power!

With best wishes,

Jüri O.-M. Ennet.



Patient web communities and their narratives

Virtual communities of patients with a serious disease are usually gathered around the union of the corresponding disease (Cancer Union, Estonian Diabetics Union).

The virtual community has a stable core member group and a flow of members coming and going.

When the forum started in 2004, there were many anonymous posts. In the first years there were also many questions and participation by family members and relatives of the afflicted. Later, the forum members are predominantly diabetics.

Threads

someone posts a personal experience narrative. third of those posted every year. Often a single person starts only one (a max of 14) such threads all in all.

Anonymous question of wide scope is posed. The anonymity of the thread beginning seems to be used as an indicator that responses from all possible contributors are welcome, and such threads quickly attract hundreds of responses.

Community

Active writers and narrators

The number of readers, lurkers, stalkers, observers vastly exceeds the actual posters.

The passive portion of the community is so much bigger.

The bridging person is the official head of the union, who is not actively involved in discussion but whose announcements are always read.

Smaller threads are read by 350, while popular ones are read 2000 times.

The range of ages reaches from teenagers to middle aged, and even retired members. Women are more active in organizing get-togethers, more active in discussions about cultural events, accessories, decorations - just as in real life. Speculatively, I would suggest that written media favors women.

The community has a strong I- and us-identity, in several topics there is a strong oppositional positioning against them - the healthy, the non-diabetic.

The central and most discussion-provoking topics.

Healthy children - is it possible to have them, what is the chance of hereditary carriage, what if the kid becomes diabetic when young, when do the unavoidable side effects like wounds and skin ailments, blindness, decrease of intelligence, personality changes, etc come.

Pharmacological help. Are there alleviating medicines, what about wonder-healers, or alternative medicine, are there any new approved good medicines. This subset includes many encouraging personal experience stories, practical advice and didactic stories.

Personal events that community members celebrate - birthdays, finding a life partner, children, marriage.

All-Estonian get-togethers - opportunity to meet face to face, which seems to have strengthened their virtual ties.

Amenities of modern life and their opportunities to take part in life fully, whether fashionable clothes and accessories can be used, daily rhythm and breaking the rules, self-help and notifying the world (special signs, wrist chains, tattoos) for emergencies.

What is the importance of such (text-based) narrative communities?

Supportive group, friends (the closes relatives are often a long way away).

Understanding and compassionate companions who are not frightened by the progress of the disease and symptoms. You are the norm and not a deviant.

From the motivational point of view, the forum also offers the opportunity to take on the role of an expert, to feel valued, needed and competent on a topic otherwise shunned.

The opportunity to present and exchange trauma and disease experience narratives.

Narrative types

Short everyday life experiences or short accounts of events, short disease experience narratives. The so-called little narratives are informative short stories that carry generalized morale - you can do anything, this is a lifestyle and not a disability, we have worth, etc., contain goals and symbols important for the community.

In many cases, narration takes place as a narrative chain of socio-cultural acts of speech, where different personal communication and narration styles as well as personal identities meets.

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. Situation descriptions are interspersed with humor and metaphoric expressions.

Example: visiting healer

The healer Viktor has been active as a folk doctor since the 1980s, he has been widely discussed in the media. He has a wide range of patients and many people have had contact with him. The following discussion forms a cohesive narrative whole, with personal experience 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.

01.02.2005 15:25

The father of my kid took the kid to the healer Viktor (in Tallinn) and he had proscribed some kind of medicine (produced by himself). 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 doctor, 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 preferation/trust of official medicine.

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 that 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.

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 tumor 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.

02.02.2005 15:30

i would never dare give some kind of x stuff to mu 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.

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.

Culmination - 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. away...

Then follow shorter (disparaging) comments from fellow forum members.

The discrete line of the narrative episode from February till April brings forth different cognitive approaches, narrativity, arguments 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.

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, The posts are short informative narratives and belief accounts. The briefness of the following episodes is caused by lack of an intriguing real life episode that would inspire emotional discussion.

Conclusion

Discussion groups are used as a replacement for the role once played by the extended family or geographical community - discussing illness and health and looking for solutions in the discourse.

Since the postmodern lifestyle and interpretations find a different set of knowledge acceptable, and is largely oriented to subjectivity, the multitude of opinions expressed in an online discussion group conforms well with the modern style.

Moral and mental support from similar people participating in online forums. They get help evaluating the state of their health, they can exchange experiences with the progress of the disease, and share their coping strategies.



The online communities can be seen as a spontaneous branch of the writing therapy for the seriously ill persons. Communication in patient forums is relaxed and includes different genres of narration and writing styles. Such groups are based on information, the shared disease experience and narratives and they play an important role in achieving mental balance.

Besides short narratives that carry information and important symbols and messages, there are also joking or didactic stories and communication threads, forming a didactic whole.

Attractive real-life events give rise to longer communication situations and narratives.

Researcher into politics and communication, Kay Richardson, pointed out:

discussion of risks and illnesses online may not be objective, but it does bring forth the issues of trust and expert judgment and teaches to rationally question political, scientific and producer the points of view forced on us daily (Richardson 2005: 209).