

On-Line Medicine. Communication and Narratives

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Health is one of the issues central to our life. Ailments are both-ersome companions that follow us around now and then. Many of the chronic diseases that even contemporary medicine considers incurable are quickly gaining ground in the whole technologically developed world. For example, consider diabetes, 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. I used here the scope of diabetes because one of the sources for this paper is the Estonian diabetes online forum.

Recent research has pointed to the erosion of community relations, increasing isolation, social fragmentation and a distancing from responsibility towards others. This also means a decrease in political, social and religious participation, voluntarism and also that 90% of adult social relations are connected with their workplace (Putnam 2000, also Shklovski & Kraut & Rainie 2004). This leads to the question whether internet communities follow the same trend or are they a substitute replacing former civil and family communities? Are they an example of transformed communication models? Besides the scientific concepts and practices it applies, the medical sphere has both a human and personal dimension. How are you coping with your illness? How do you live your daily life? What does the internet and virtual communities give you?

Within the research grant „Internet. Processes of construction, reproduction and transformation of narratives, values and identities” (ETF6824) my area of research has been on-line medicine and new religious on-line communities. In addition to their communication strategies and key values characteristic of the community, I viewed their communication opportunities and narratives. My aim is to overview the types of communication that have changed the logistics of doctor-patient communication, e.g. online medical information and narratives, communication acts.

Inter-doctor communication benefits from the possibilities for professional communication, and application of multi-professional knowledge; it helps shape and unify professional terms and nomenclature, guarantees the confidentiality and security of data, while providing easy management of high-quality data; makes provisions for knowledge management and ambulatory e-services. I consider here the narratives in the forums www.kliinik.ee and www.diabetes.ee which redistribute medical information and personal experience stories.

MEDICAL INFORMATION ON THE WEB

With the expansion of multimedia, in the late 1990s e-medicine became in Northern Europe and North America with funding from the national governments and the big medical corporations a “big business.” The large information management systems and support became a political issue.

The 1990s saw the emergence of great medical resources online, initially from personal initiative and later as state policy. Troves of knowledge accumulated in portals and mailing lists. Official home pages of medical institutions, information about academic teaching and research centers as well as international professional unions became easy to find online. These sites also published useful information on, for example, general medical terminology, techniques, etc. There was also historic discourse: writings about the history and founders of the disciplines, propagandist calls upon people and user feedback interfaces (see e.g. Estonian Midwives Union). The portion dedicated to professional schooling and self-improvement has constantly increased.

All large medical online portals have, from the beginning, been specialising in providing different kinds of information. Arst.ee (www.arst.ee, *arst* ~ doctor) is a portal uniting professional medics and institutions. Since it opened in 2005, it has offered free online advice requests and the service is ever popular. The site claims to contain information about more than 13,000 medical workers, 1500 institutions, 2500 drugs and about 35 diseases (www.arst.ee). A similar site, inimene.ee (www.inimene.ee, *inimene* ~ human) introduces doctors who hold family practices.

Use of computer-mediated communication has brought a change to the logistics of communicating with the patient. Following the course of a disease, finding suitable drugs as well as other doctor-patient communication aspects became more easily manageable for both the medical workers and the patients. That is why already in the mid-1990s the great perspectives of computer mediated communication in medical science and inter-doctor communication were emphasized: in addition to professional communication, computer network allows to share and distribute medical and multi-professional knowledge and shape the professional terminology and nomenclature, as well as use groupwork in medical practice. At the same time, guaranteeing the quality of data is easy, data management is easy and it can be used to carry out monitoring actions and develop research. The fast installation of network to clinics and use of personal workstations as well as the spread of computer mediated communication was inspired by the need of saving, maintaining and processing patient data. The wide range of opportunities offered by and use of computers is made certain by the statewide introduction of e-patient cards. In this field we can also see a constant development, for example in May 2008 East-Tallinn Central Hospital was the first to make e-patient histories accessible to ID-card users (BNS 2008).

Computers and internet make helping the patient easier, considering that family practitioners usually have a patient list of up to 2000 people (www.perearstikeskus.ee, *perearstikeskus* ~ family practitioner centre), and their primary task is to provide a preliminary diagnosis, treat general diseases, provide health advice, prophylactic care and referrals to specialists when necessary. Today, only single family practitioners have their own website, they use both phones and e-mail to communicate with

the patients, and the phone is the more prevalent means. The phone is in the lead simply because it is a direct interactive emotion-carrying means of contact. We should also take into account that people talk faster than they write, saving time for both parties. One should also consider the calming effect oral contact has on the patient. E-mail is, however, well integrated into everyday communication as an administrative tool for dispensing formal information, e.g. test results.

Medical information online can be divided according to who is the provider and the target group: medical information for medics, from medics to patients, from patients to patients. Historically, health information has been a sphere reserved for specialists and medical knowledge has been strictly related to a career in the profession. Knowledge was protected by the high price of the service and the to an extent esoteric closed nature of the professional community. The side-branch of medical knowledge – vernacular healing – includes a wide and profitable network of publications that has profitably operated without input from top medical practitioners nor top medical researchers.

In the more liberalized medical circles, professional medics are more and more often engaging in dialogue with future and current patients. They often provide general information and advice for the wider public – which is one of the fastest-growing medical internet services.

We expect online medicine and online education to be a trustworthy source and to provide a good level of help via the internet. Of course, the user is the one who decides which e-medicine services to use, who to consult, who to trust and whose advice to follow. To find trustworthy medics and websites, the common source is feedback from personal social networks, but also the medical discussion groups and everyday online networks. Opinions given in medical discussion groups indicate that the most trusted consultants are the ones who are institutionally affiliated and have documented proof of professional degree. Making advice from a network of vocational medics available to patients and the healthwise uninformed gives them the best quality of online help.

NARRATIVITY IN THE DOCTOR-PATIENT FORUM

Every patient has the right to get information about and additional opinions on his health from an independent medic. Getting a reliable opinion from professionals helps reduce illness-related stress. Information portals manned by medics and for the layperson give authorized information on specific medical problems, provide complex e-service packages, notify of new drugs and publications in the field, give advice on diet and food consumption; they also support discussion groups. A patient has the option to remain anonymous, but my observation is that people often provide actual personal data or first name and age.

The largest advice portal in Estonia is the site *kliinik.ee* (*kliinik* ~ clinic), with *arst.ee* (*arst* ~ doctor) provide multifaceted information: online diagnosis and opinion on treatment scheme.

Information provided by medics is usually free of charge, with the exception of one portal where some of the doctors take a symbolic fee (<http://www.kliinik.ee/index.php?4>) – 5–10 EU. In addition to professionals of various physical ailments, there are consultations by psychologists as well as pharmacologists, there are links to useful articles, interviews, health tests and topical discussions.

The site *kliinik.ee* not only helps get instant and specific answers, but earlier questions and answers form a local archive and ultimately a large corpus of disease narratives. Going through the corpus of data about any one disease gives one an overview of the disease progress, healing methods and symptoms.

A discussion board gives users the opportunity to discuss health-related topics among themselves. It is noteworthy that the range of topics discussed in forums is narrower than that discussed with consultants, and the communication style is more similar to general discussion forums like *delfi.ee* or any other portal that hosts topical discussion forums.

Doctors and patients follow different cognitive models and represent not equal but different socio-political interests (cf Kleinman 1980; Singer & Baer 1995: 375). Indeed, the environment gives rise to specific choices in language usage, the 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 percep-

tion 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. As mentioned above, official forums maintain the anonymity of the patient, while patients often decide to suffice self-presentation by giving a first name and age, or a broader geographical region. The doctors, however, write under their full name, adding weight to the value of their expert judgment.

Let me present an example from a doctor-patient forum:

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 attended 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.

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

Märt Elmet

The poster uses formal language to pose the question. This is characterized by choosing words not used in oral speech but common in medical jargon. The case history is also striving for accuracy. Such pretensions to objectivity in written narrative are close to the real-life patient-doctor dialogue, except here there is no dialogue development and the communication is limited to one exchange. We could view a patient story as a short formal and informative piece of communication. Narrative components are simple and repeat from one story to the next. In this case:

A: greeting, self-presentation, earlier case history, information of medicines used, question about diseases, thanks.

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

evelin cardiology 19.02.2008

pain in chest

Hello, I am a 28-year-old woman. The problem: after the birth of my second child (2007 Nov) I developed chest pains that are now projecting to my left hand, back and neck. I feel a constant mild pain in the back, shoulder and arm and then sometimes a strong, sharp pain stabs in the chest, projecting slightly to the shoulder (the pain lasts about 3–5 sec.) Family doctor gave me the drug Preductal, which is what I am taking.

But I would still like to find out, what causes such pains? Maybe it would be better to not take drugs and what does it help against, after all? What to do?

Answer: Märt Elmet 25.02.2008

Hello,

It is impossible to determine by your letter what causes the pains.

In young people, chest pains are often related to chronic nerve or muscle inflammation. There are other possible causes, but these should be investigated by the family doctor.

Preductal is proscribed to enhance the metabolism of heart muscles in case of blood vessel atherosclerosis. It probably has little effect on your condition.

Märt Elmet

Also this poster uses formal language to pose the question, also a bit of medical jargon. After the short description of the history of illness she asks for expert opinion.

A: greeting, self-presentation, earlier case history, information of medicines got from doctor, asking for expertise.

B: greeting, an evaluation of the patient, case history, suggestion to get further opinion from family doctor. Evaluation of drug. Signature.

The doctor and patient are carriers of different cognitive models and in an act of communication they participate as partners with different interests. To gain objective expert opinions requires regard to certain communication norms just as in a real life visit: greeting, introduction by name (the sex of Estonians is in most cases obvious from the first name) and a few minimal introductory sentences, diagnosis, etiology, administered drugs, reactions. The doctor's reply is in neutral language, giving an opinion on the symptoms and drugs. In addition to providing expert evaluation, the doctor's narrative should give advice and warn of possible dangers.

Another important function for the Q&A is testing how serious a problem is. It is not rare that the doctor urges to get analyses done quickly, warns of danger, suggests calling the ambulance, etc. This helps patients get over a mental barrier that, at least in Estonia, does exist – nobody wants to trouble a medic with trivial symptoms to avoid being ridiculed as a hypochondriac or eccentric.

Doctor's answers in any other key are rare. Here is an example of a case where a licensed psychiatrist acts almost as a prophetic preacher:

Honorable Mr. Ennet!

I would like to ask You 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 of 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 the mood gets better. Consequently – keep diabetes under the wise guidance of the endocrinologist and guide those hormones of happiness with 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.

Have strength!

With best wishes,

Jüri O.-M. Ennet

The aim of the text is to give the patient a positive feeling and inject a piece of optimistic outlook. Still, the style of this one doctor is exceptional in the portal and his replies have minimal structural differences between them. Doctors have also other individual style differences in how often are drugs recommended and if then how much background information is provided about them.

There are some, though few, cases where a patient asks for help recurrently or when the doctor recognizes a previous patient – in such cases, familiarity induces personal warmth and emotions in the dialogue. This way, even the formal situation can lead to communication through repetitive speech turns or a personal connection between the patient and doctor, leading to a relaxation of the social barriers.

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, etc.). Discussion groups that unite patients with a common diagnosis or patients in general have a more relaxed communication style and do not have such clearly structured narration patterns or writing styles.

If we take into consideration the fact that individual identity is constructed in social interaction, during which one's self is both determined and re-evaluated and redefined according to life experience, then we can see the main reason why a certain forum or topical discussion group attracts people who have survived a trauma, disease, act of discrimination, or people who are in a crisis situation.

One of the most important factors inducing people to participate in the discussions is the opportunity to present and share personal experience stories about traumas and disease narratives, an opportunity that people often find they do not have with their regular social network. Although relatives and friends are likely to listen to a short-term repetition of disease narrative, it is psychologically difficult for them and they do not know how to adapt to this. Workplace acquaintances often ward negative emotions and do not act empathically towards the disease and suffering of a colleague. This can traumatize the patient and lead to his ostracism from the community or, in drastic cases, to loss of job position.

Web forums uniting people with difficult or fatal health problems can help the afflicted support each other morally and spiritually, to analyse their state of health, to exchange tips about making things easier, share successful healing stories, teach coping strategies and – once again – help each other with the question of why did I have to fall ill.

There is more and more attention to the writing therapy for the seriously ill, with a spontaneous branch budding online. Forums for diabetes, cancer and other difficult/ impossible to cure disease patients are found everywhere. The internet setting has several advantages, for example the fact that it is not a monologue, but a dialogue with people in a similar situation. At the same time, it is possible to keep one's privacy and anonymity, to the extent they desire this.

In the diabetes online community, the virtual community has a stable core member group and a flow of members coming and going as they get older or migrate and go through other life changes. When the Estonian forum for diabetics opened 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, majority of forum members were diabetics.

The community of diabetics follows the model of the real society in its division of roles, activity, etc. The range of ages goes from teenagers to the middle aged, and even retired people. 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 favours women.

We can see that typically to all open web communities, the number of readers, lurkers, stalkers, observers vastly exceeds the actual posters. Smaller threads have been viewed by 350, while popular ones are viewed more than 10000 times. The passive portion of the community is so much bigger. The bridge person between the active and the passive is the official head of the union, who is not actively involved in discussion but whose announcements are always read.

The diabetes community has a strong I- and us-identity, in several topics there is a strong oppositional positioning against “them” – the healthy, the non-diabetic. For example, when discussing how and in particular how dangerously distorted is the image THEY paint about diabetics. One point is that the American movie industry uses diabetics often as the general figure of an afflicted person and if people followed the instruction shown in movies – get the syringe from his pocket and give an injection – a real diabetic would probably die. This can also be seen as an example of the cocktail party effect – out of all the background noise, you clearly pick out your own name, or in this case, the mention of your affliction.

THEMES OF DISCUSSION

Threads fall into two main types. The first type is where someone posts a personal experience narrative. This kind of posts

form up to a third of those posted every year. Often a single person starts only one (a max of 14) such threads all in all.

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

An interesting picture is painted by what are the central and most discussion-provoking topics. Naturally, the gamma of topic is different from that of pet-forums, SF, geocaching, etc. interest communities. In the diabetic community, the most central worry is around healthy, unafflicted 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.

The other great block of interest circles around 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. And also other 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.

Virtual community events include personal events that community members celebrate – birthdays, finding a life partner, children, marriage. But there are also real-life events for the virtual community. The first all-Estonian get-togethers were major events as they offered the opportunity to meet face to face. And having met face to face seems to have strengthened their virtual ties.

IMPORTANCE OF (TEXT-BASED) NARRATIVE COMMUNITIES

In our changed society where urbanization has reduced family size to the nuclear family, the closest relatives are often a long way away. This means you are more likely to find friends and

similar minds among work colleagues – or online, in shared interest groups.

For the patient, the online environment and web-mediated communication gives, in addition to medical information and expert evaluation of healing scheme and disease, also the opportunity to take on the role of expert. The forum also offers the opportunity to feel valued, needed and competent on a topic otherwise shunned.

The virtual community has an equally important function: they are understanding and compassionate companions who are not frightened by the progress of the disease and symptoms. They offer the opportunity to discuss topics that are unwelcome in a general social setting, your problems and get competent advice. Here, you are the norm and not a deviant.

Since postmodern lifestyle and interpretations recognize various forms of knowledge and is oriented to subjectivity, the multitude of contradictory opinions presented in a discussion group corresponds well with the modern style. In many ways, this opposes to the rational objectivity so much valued in molecular biology and medicine.

The opportunity to present and exchange trauma and disease experience narratives is really very important if the afflicted do not have a spiritually close person they can interact with face to face. We should also not ignore the rule of thumb that relatives and friends do not mind a few repetitions of disease narrative, but they do not (know how to) respond in a supportive manner. Protecting oneself from depressing experience and showing little empathy towards the fellow person's illness and suffering is typical of contemporary society. This can even go as far as causing the afflicted a psychological trauma or social ostracizing or, in drastic cases, loss of employment.

NARRATIVE CHAINS

The majority of stories told in the community are short pieces on everyday life or short informative accounts of events. 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., they contain goals and symbols important for the community.

In many cases, narration 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. 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 that case texts are in complexity, but we as readers can divide a text into ambiguous and unambiguous regions.

I am going to next present as an example a communicative narrative chain, a discussion about an alternative medic. 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 and 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 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).

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. In addition to providing diagnoses and healing, there is a number of homes that bought Victor's healing painting. The following discussion forms a cohesive narrative whole, with personal experience and narrative insertions from various parties. Such narration is characterized by Monika Fludernik's term natural narratology or spontaneous conversational storytelling (Fludernik 1996: 235). Manfred Jahn suggests that Mark Turner has recently demonstrated that "most of our experience, our knowledge, and our thinking is organized as stories" (Jahn 2000). The

initiator is the story of a kid's father's visit to the healer Viktor is the mother asking people their opinion of whether the visit had a point at all. The first question, itself part of a reportable event, initiates a chain of communication acts (see Discussion 2008).

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 preference/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.

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, argumentation skills (?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. The discussion is joined by both people who themselves or whose relatives or friends have positive experiences with that folk healer or some other folk healer. Their opposition is made up of skeptics, people with negative experience stories, the prejudiced, the upholders of official medicine or those convinced of the efficacy of chemical drugs.

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 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.

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, also it is the *resolution* of the narrative.

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.

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 probably caused by lack of an intriguing real life episode or narrative that would inspire emotional discussion. Unlike on the doctor-patient forums, the writing style here is emotional and personal, making use of all the means of expression offered by the written medium. We can see quotation marks denoting pauses, all caps for loud voice or insistent intonation, written shorthand for paraverbal and emotional expressions (e.g., LOL). Full stories or episodes are alternated with freely associated trains of thought and argumentation. Any one discussion is made up of the speech acts of different participants, some of them narratives, story-like forms, some of them claims, assertions, counterclaims, making up a complete discussion for the reader. Since we form our own impression of the event and its surrounding discussion based on what we read, we do not actually feel the time gaps between actual posts spread out over days but see it as one unit. Therefore, every narration is split between two realities: a communication process progressing from compressed to expanded, direct narration and communication, and secondly a readable authored story. This has maintained the authorship of different parts. A story read is more compact than real-time communication that lead to the creation of the final written story. Significantly, people present stories in the first person, their own generalizations, experience, but for argumentation give examples of second or third person stories or refer to such. The number of communication acts on the patient forum can be 1 to over 300 posts/stories. What is it that unites the stories with so different numbers of communication acts? Monika Fludernik links the narration with its human experiencer: "In my model there can be narratives without plot, but there cannot be any narratives without a human (anthropomorphic) experiencer of some sort at some narrative level" (Fludernik 1996: 9).

CONCLUSION

It is easy to see how 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. Nevertheless, people act differently in socio-culturally different situations, using also different styles of narratives.

Communication on doctor-patient forums are characterised by a certain beginning, central point and ending commonly found in classical narratives (cf Thornborrow & Coates 2005: 7), a short and clear structure. Also, communication takes place on unequal levels where the patient is the subordinate with a lower position. This leads to neutral wording and a limited scope of information exchange (only the specific complaint and related information).

Communication on patient-patient forums is relaxed in the range of styles and topics, closer to how an offline interest group interacts. 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), 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 created oriented to disease-specific groups have several advantages in this respect, in fact. They offer the opportunity for dialogue with people in similar situation. At the same time, it is possible to maintain privacy and anonymity.

Communication in patient forums is relaxed and includes different genres of narration and writing styles. This ranges from simple informative announcements, claims, arguments to both simple and extended natural conversational or even classical stories. 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. Such groups are based on first-hand information, the shared disease experience and narratives and they play an important role in achieving mental balance. Typically of internet communication, in addition to realtime communication and storytelling, even in the case of interrupted and sporadic information and communication flow, it is important that the communication act is archived as a single readable unit. In this way, the forums produce permanent information, narratives and texts that can be repeatedly used and interpreted. Communicative narration chains analysis points to advantages in adopting William Labov's approach. This allows us to evaluate stories on the scale of their reportability and credibility, to differentiate between textual structural elements like orientation of the narrative, the resolution of the narrative, coda, etc.

Medical forums spread not only narratives, but also folk belief. Researcher into politics and communication, Kay Richardson, pointed out in her book *Internet Discourse And Health Debates* (Richardson 2005: 53 ff) the influence various media channels have on oral/written internet heritage: "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).

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References

Arst.ee (<http://www.arst.ee> – July 4, 2008).

BNS 2008. *Ida-Tallinna keskhaigla tutvustab iPatsiendi portaali* (http://www.delfi.ee/news/eesti/eesti_uudised/article.php?id=18693065 – July 4, 2008).

Chambers, N. & Jurafsky, D. 2008. Unsupervised learning of narrative event chains. *Proceedings of ACL-08: HLT* (pp. 789–797). Association for Computational Linguistics.

- Discussion 2008 = discussion thread on healer Viktor in Estonian Diabetes Association forum (<http://www.diabetes.ee/foorum-teema.php?lk=10073> – July 4, 2008).
- Estonian Midwives Union = Eesti Ämmaemandate Ühing (<http://www.ammaemand.org.ee/index.php?id=387> – July 4, 2008).
- Fludernik, Monika 1996. *Towards A 'Natural' Narratology*. New York: Routledge.
- Inimene.ee: Terviseportaal (<http://www.inimene.ee> – July 4, 2008).
- Jahn, 2000. Stanley Fish and the Constructivist Basis of Postclassical Narratology. Bernhard Reitz & Sigrid Rieuwerts (Eds.). *Anglistentag 1999 Mainz: Proceedings*, pp 375–387. 1999 draft version. <http://www.uni-koeln.de/~ame02/jahn99xa.htm>
- Kleinman, Arthur 1980. *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine and psychiatry*. Comparative studies of health systems and medical care 3. Berkeley: University of Californian Press.
- Kliinik.ee (<http://www.kliinik.ee> – July 4, 2008).
- Labov, William 2007. Narrative pre-construction. M. Bamberg (Ed.). *Narrative – State of the Art*. Amsterdam & Philadelphia: John Benjamins, pp. 47–56.
- Labov, William 2004. Ordinary events. Carmen Fought (ed.) *Sociolinguistic Variation: Critical Reflections*. Oxford: Oxford University Press, pp. 31–43.
- Perearstikeskus.ee (<http://www.perearstikeskus.ee> – July 4, 2008).
- Richardson, Kay 2005. *Internet Discourse And Health Debates*. London: Palgrave & MacMillan.
- Singer, Merrill & Baer, Hans 1995. *Critical Medical Anthropology*. Critical Approaches in the Health Social Sciences; Political Economy of Health Care. Amitwill, New York: Baywood Publishing Company.
- Tartu Ülikooli Kliinikum (<http://www.kliinikum.ee> – July 4, 2008).
- Thornborrow, Johanna & Coates, Jennifer 2005. The Sociolinguistics of Narrative: Identity, Performance and Culture. *The sociolinguistics of narrative*. Studies in narrative 6. Amsterdam: John Benjamins, pp. 1–17.



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