

THE ROLE OF ONLINE ILLNESS COMMUNITIES FOR OLDER PEOPLE: BETWEEN INTERACTIONS AND KNOWLEDGE

ULOGA ONLINE GRUPA ZA BOLESTI STARIJIH LJUDI: IZMEĐU INTERAKCIJE I ZNANJA

APSTRAKT Rad ispituje ulogu online zajednica (foruma) o bolestima starijih ljudi koji žive u ruralnim oblastima Rusije. Internet zajednica za bolesti predstavljaju su veb stranice na kojima se bolesni ljudi i lekari udružuju kako bi saradivali, komunicirali i pronašli informacije o liječenju. Empirijska osnova studije se zasniva na 25 biografskih intervju sa starijim ljudima koji su živjeli u ruralnim oblastima i imali su razne hronične bolesti. Svi učesnici su bili članovi velike internet zajednice poznate u Rusiji i zemljama ZND. Studija analizira online zajednice koristeći okvir interakcionističkog pristupa i ispituje kako se gradi laičko znanje u takvim zajednicama. Na osnovu analize empirijskog materijala identifikovane su tri strategije za interakciju starijih ljudi u online zajednicama za bolesti.

Ključne riječi: stariji ljudi, online zajednice za bolesti, interakcija u online zajednicama za bolesti, stariji ljudi u ruralnim oblastima Rusije, stariji ljudi sa hroničnim bolestima.

ABSTRACT The article examines the role of online communities (forums) of the disease for older people living in rural areas in Russia. The Internet community for the disease is web sites where sick people and the doctors come together to cooperate, to communicate and to find information about the treatment. The empirical basis of the study is 25 biographical interviews with older people who lived in rural areas and had various chronic diseases. All the participants were members of a large Internet community known in Russia and the CIS countries. The study analyzes online communities using the framework of an interactionist approach and examines how lay knowledge is constructed in such communities. Based on the analysis of empirical material, three strategies for interaction of older people in online communities of the disease were identified.

Key words: older people, online illness communities, interactions in online illness communities, older people in rural areas in Russia, older people with chronic illnesses.

Background

Contemporary health and healthcare are steeped in neoliberal principles, from the hospital and state healthcare systems to the individual patients. One way to integrate neoliberal treatments are online illness communities where patients can get the necessary advice on how to treat illness. Individual patients today enjoy autonomy in their healthcare, but this has come at the hidden price of a greater expectation for patients to take personal responsibility for their

health and bodies. However, the role of online communities in the treatment is twofold. On the one hand, online communities play an important role in the process of self-choice of treatment by the patient, but on the other hand, they can disrupt the treatment process with wrong advice and wrong treatment of the illness. In this research participation in online illness communities is hypothesized to be a buffering mechanism that would facilitate older chronic patients with how to cope with illness in everyday life. Communication in online communities is suggested to be a comforting aspect of the group support where older people with chronic illness can talk about their illness and talk about the difficulties of experiencing the illness and get the necessary advice. On the other hand, in the study, I focus on exploring how the creation of knowledge about how to treat illness occurs as part of the participation of older people in online communities. The research question of the study is: How technology such as online communities can change the experience of illness and the daily lives of older people with chronic illnesses?

Methods and data

Online illness communities are websites where ill people and doctors convene to collaborate, communicate, and find information about treatment. Communication in online illness communities takes place via forums and symptom logs. Communications on forums consists of “threads” of postings displayed in reverse chronological order. Data source is a large online illness community at which several thousand patients meet daily to share knowledge and support. The patients in online illness communities have different biographical backgrounds and different illnesses. The patients from online communities are mostly older people from cities and villages of Russia and CIS. There are also young people in the communities who are experiencing serious chronic illnesses. There are also doctors in the communities. The doctors participating in the communities are therapists, cardiologists and surgeons. Basically, the role of doctors in the communities is to give advice to patients and moderate some conversations in the chat. Communities members register for free, select an anonymous username, and fill out a simple public profile in which they can specify their location, occupation, and interests. The communities also feature a chat room, blog, informational resources for various conditions, a bookstore, and a community newsletter.

As a part of this research, I conducted biographical interviews with participants (n= 25). All my participants are residents of the Luga district of the Leningrad region, Russian Federation. They all have various chronic illnesses. As a rule, these are cardiovascular illnesses. Among my participants there were people with cancer and strokes. My participants are between 65 and 88 years old. Among my participants there were people who lived alone and those living with their families. I also conducted observations on how the older people use

and interact in the Internet online illnesses communities (Internet ethnography - ethnography of posts and structure of the online community).

Theoretical background

The first approach I used in the study is symbolic interactionist paradigm. In the first case, I analyse how interactions occur in online communities and how knowledge is constructed. The second approach that I use in the study is a *fluid technology* developed by A. M. de Laet and A. Mol. The concept of *fluid technology* allows me to consider online communities as a technology that adapts and integrates to the conditions of rural life. (De Laet. et. al, 2000).

It is suggested in medical sociology literature that interaction between Internet technology and health care consumerism is promoting «information age health care system» in which health care consumers use the information technology to gain access to medical information and control their own health care (Eysenbach, 2000; Ziebland et. al, 2012: 219). Accordingly, we can argue that the sick role and the patient role has been changing due to the changing technological and social trends of creating new cohorts of technology used by health care consumers (Schnittker, 2005).

Symbolic Interactionism is a sociological paradigm that can be used to better understand the illness experience of older patients since this paradigm embeds that perception of the self and identity within a social context and links illness associated cognitions to behavioral manifestations. The symbolic interactionist paradigm focuses on individual and group interaction provides us a framework to understand the link between individuals' and interactions with other peoples (Fife, 1994).

Social support from others may offer an alternative view of the situation and alter the perception of the illness (Fife, 1994: 316; Zhao, 2005:387). One of the factors that influences the process of adjustment to an extremely stressful life event, like chronic illness, is to find the meaning in the event by the communication with other patients and to incorporate it into the personal life course history (Lechner et al., 2003; Bowman et al., 2003: 226; Crossley, 2003: 440). Social support can play an important role in finding meaning in the experience by offering alternative views on the chronic illness experiences and by representations of the illness experience (Linley et. al, 2011:152; Burrows et al., 2000:120; Hardey et. al, 2002:31; Stelfson et. al, 2013). Talking about the chronic illness and sharing a supportive context like online illness communities is associated with a positive reappraisal of the experience (O'Hair, Scannel Thompson, 2005:94;, 2005; Beck, 2005:79; Babrow, Kline, Rawlins, 2005:31).

Sociological literature classifies social support into three main categories: emotional support, informational support, and instrumental support (et al., 2001). The first two categories of support are useful for the types of support observed in online illness community. In this study I highlighted the strategies

of communication and participation in online illness communities according to these types of social support. Emotional support refers to listening and providing the person with sense of love, respect, sympathy, comforting, encouragement. It also refers to the ability to share one's thoughts, emotions with other members of the community (Schroevers et al. 2003: 378). Informational support refers to provision of information to the members of the community. In the context of chronic illness, recommending a physician to another patient or making suggestions about different medicines or daily regimes based on personal experiences could be examples of this type of support. Instrumental support is support of the members with concrete problem e.g. help, physicians' advice about hospitals and medical operations or support with medicines e.g. by sending medicines by post. This is a very concrete type of social support that deals with concrete problems, not advice as informational support.

Another important concept in the study is the construction of knowledge that occurs in online communities through interactions with community members. One major development of this sociological turn in science studies was a shift in empirical focus to non-expert forms of knowledge. I will refer to this eclectic variety of knowledge as a *lay knowledge* concept. This knowledge is usually opposed to the traditional laboratory knowledge of scientists which is produced in laboratories, whereas scientists and doctors have expert monopoly over such knowledge, according to the work of B. Latour (Latour, 1979; Wolpe, 1985). For a basic definition of lay knowledge, I use Berger and Luckmann (Berger and Luckmann, 1966), who famously conceptualized knowledge as the basis for the entire social construction of reality. Parting ways with previous scholars of knowledge who focused only on expert scientific knowledge, they emphasized the importance of "everyday life 'knowing,'" which includes "an assemblage of maxims, morals, proverbial nuggets of wisdom, values and beliefs, myths, and so forth" (Berger and Luckmann, 1966:65). In the realm of health, lay knowledge often combines medical, psychological, and social information to form a colloquial understanding of different health conditions (Krause, 2003: 599; Bernardi et. al, 2017).

Instead of automatically taking the experts' opinion, people integrate scientific knowledge into pre-existing pools of "supplementary knowledge"—which is comprised of lay understandings and beliefs. That is, lay knowledge does not represent receptacles of expert knowledge, but rather processors of it (Berger et. al, 2005; Wagner, 2007: 19; Foster, 2016:31).

Thus, online communities has an important role for older rural residents as it is in such communities that the agency of older rural residents is constructed and here there is an opportunity to consult with experts regarding their diagnoses.

The concept of *fluid technology* proposed by M. de Laet and A. Mol and designates fluid technology as the most convenient and comfortable environment. This technology is able to easily integrate under different

conditions of everyday life and be as useful as possible. M. de Lae andt A. Mol do not note that this technology can be considered as exclusively good (De Laet. et. al,2000:261), but I believe in the study that this technology is a benefit that allows older people in rural areas to receive emotional support and promotes communication and exchange of knowledge with other people living with a chronic illness. Fluid technologies of online communities produce lay knowledge and this is very important for rural older people. In the study, I look at interactions and knowledge creation in online illness communities and try to answer the question of how fluid such communities can be?

Findings

Analyzing biographical interviews, I highlighted three scenarios of communication, interactions and use of online illness communities, each of which is characterized by its own understanding of the online illness community and their role in everyday life. Biographical interview data and observations show varying degrees of involvement in communication, interactions in online communities and the use of online communities.

Communication strategy

The participants in this scenario are usually older people who live alone in rural areas and who have relatively recently started to use the Internet and have a short experience with the illness. For such participants, the primary importance of online communities is the ability to communicate, discuss health issues, and participate in illness communities:

«Now, if it weren't for the computer, I probably would have been unable to communicate with anyone here at all, I don't really like the neighbors, they are kind of muddy, and here at night and day there is complete silence in the whole village. That's why such online communication helps and a laptop is a rescue, there you'll at least share it, tell about the illness and everything will become easier» (participant 1)

Those older people who chose a *communication strategy* noted the importance of emotional support in online communities. When writing messages in forums, the representatives of this strategy, as a rule, use an emotional style of online communication, with a large number of exclamation points and interjections, and a preference to listen over telling about oneself:

«To be honest, I almost always sit in the online community and almost like this every time I describe my illness enough, the course of my illness, with possible, I don't know, ways out and ways to treat the illness, which I indicate in the descriptions of the illness» <...> (participant 2).

That is, when communicating with older people about choosing a scenario for presenting the illness, it is important for the community to use often-stoic descriptions of illnesses, possible problems and lesions. Not infrequently, I notice gaps related to the fact that in an interview illness is

described as much more complicated and the struggle against the illness takes on completely different shades than the description of the same illness in the forums. That is corporality in describing the illness was mainly not brought to the online space by the representatives of the *communication strategy* as it is associated mainly with offline communication, but the stoic experience of the illness occupied a central plot line when communicating on forums:

«I can tell you this, how difficult it is, how difficult it is to live with the illness like this every day, I can share with the doctor, but the Internet, in general, is basically not for this from the beginning here either to write a lot of positive or write nothing. I remember the story of how I waited for an ambulance for three hours in Luga and almost like that, for three hours and how I didn't die, and wrote like that, they all gave me attention, they gave advice, and I can say so and talked about our medicine with beautiful, who else to share, and people warned of possible dangers that could happen» (participant 3)

Confidence of the advice of the representatives of the *communication strategy* is based on positive advice, which is highly recommended, but not edifying. Moreover, since the forum is attended by doctors of various specialties, the representatives of the *communication strategy* say that in this case diplomatic style of advising by doctors is most important, where doctors do not demonstrate their expert status:

«I don't like it when in forums on the Internet, people come to our community, for example, doctors there who think they are demigods, that is, everyone knows and knows how to properly treat the illness. This I do not accept. Probably, the best thing for me is this style I don't know what else is in communication ... when I write my posts, and some of the doctors or nurses try to comment on it, but I do it in such a confidential manner without using different ones there scientific words, expressions and so on» (participant 4).

Also, representatives of the *communication strategy* noted that it is important not only to talk about the experience of the illness itself, but also to tell the stories related to what life is like with a chronic illness in a rural areas. Since members of the online community are people from different places and from different regions, such topics as improving life in the village, making infrastructures more convenient, economizing the use of hot water, electricity and gas in the village or the absence of communal infrastructure are very often described by older people. Their narratives often point out the problems caused precisely by the countryside life and those related to the peculiarities and difficulties in experiencing chronic illness. In addition to discussing chronic illness, an opportunity arises to tell about other problems of living with the illness and get emotional support on completely different issues: *«here we have old people living in the Leningrad region, they will cut off the stove, then the lights will be turned off, something else will happen and then there's nowhere to go if you want to live and live like that, otherwise a bunch of problems just falls on your head, so today I'm telling you how they cut off the light at three at the*

night and switched it back on only at five in the evening, sit like that and don't know how to take a pill» from a post in online New Health illness community¹). Moreover, as older people with chronic illnesses wrote about themselves, sometimes stories about life in the countryside played the role of stoic stories, stories about how difficult it is to just live in a village and live with a chronic illness. This example illustrates the inscriptions used in microsociology when one of the things, for example a game object, ceases to be a game object and acquires new scenarios according to the concept of D. Ball. In this case, the online illness community becomes a community for discussing housing problems, rural life ethnography and descriptions of its difficulties (Ball, 1967). Such a scenario is quite typical of the representatives of the communication strategy, that is, the familiar scenario is broken and the illness community is not used for its intended purpose, but as an opportunity to receive emotional support. It should also be noted that the representatives of the communication strategy preferred to communicate mainly with people of their age and tried to avoid communication with young community members. That is, in some cases, the communication of the representatives of the *communication strategy* can be described as quite selective and most often the communication was built precisely with people of their age, with whom it was possible to discuss important and necessary things regarding the treatment of the illness.

Users strategy

For the representatives of the *users strategy*, the characteristic feature is not a periodic violation of the communication scenario, as is typical of a communication strategy, but the following of the general concept of the online illness community, or rather a structural branch of this concept, namely the search for necessary and important tips that can be found both in the discussions on forums, and in communication with other people, something for which the community itself was originally conceived. As a rule, unlike the representatives of the *communication strategy*, the representatives of the *users strategy* join online communities less often, and only when it is necessary to solve some health problem or in cases of sharp remissions or a sharp deterioration: *«I don't go there very often, but sometimes I go there just to find the advice I need, I recently found the necessary prescription and started using this medicine and if it weren't for the community, where could I find it, but here it's easy just found»* (participant 6).

The representatives of the *users strategy* prefer to communicate in the forums and post the necessary information when it is really necessary to ask for advice. As a rule, the representatives of the *users strategy* are those older people who live with their families or relatives and one of the explanations for the quick use of online communities was just the lack of the right time to communicate in the community. It is also important that the representatives of

¹ The name community is anonymized according to the ethical program of the study.

the users strategy, as a rule, communicated with neighbors and maintained fairly close relations with them, which, of course, had an impact on how communication took place in the communities and on understanding the instrumental role of online communities: «two years ago, when my daughter was still living with us, she bought me a laptop that was not expensive HP and since then, it happens, no, no, and I'll look on the Internet, but I entered the community when I was looking for my record well, there's a long series of links to the doctor, and as a result, a link to the person I need and then I read, liked the material, liked that the therapist speaks there, generally writes about illnesses and treatments, well, in general, as a result, I and joined the community» (participant 7)

The representatives of the *users strategy* noted that they were guided by the Internet community, as a community of experts and trusted the opinion expressed there by both doctors and other patients with similar illnesses. Often, the representatives of this strategy say that there was much more useful content for treating the illness in the online community than simply in the directories or on forums on the Internet. Therefore, the communication in online communities was important in terms of finding new opportunities and ways to treat the illness, then the psychological help could move to online - communities and the transit is accomplished just on the basis of trust in the online - community. For the members it is important not just to read the tips but also to implement them, follow these tips.

For the representatives of the *users strategy*, it is typical to follow the scenario prescribed by the online illness community and, largely, the online illness community is rather used to get the necessary advice or recommendation on how to treat the illness than to communicate with other people who use these communities. A breakdown of the scenario, namely flood and the use of various, as they called, participants of this strategy «rubbish in chat», are more likely negative consequences for the treatment and visiting sites of representatives of the *users strategy*. That is, long communications and long stories about the illness can also help older people leave the online community and leave the chat itself, and usually then they do not enter other communities to communicate and discuss the illness and their condition with them. One of the important research observations is the observation that older people who chose a *user's strategy* display satisfaction with rural life, in contrast with the representatives of the *communication strategy*. Usually, the representatives of the *users strategy* ask for advice on medicines, replacing medicines with generics, and the possibility of using certain medicines and their benefits.

Monitoring strategy

For the representatives of such strategy, it was important to observe how communication occurs in forums, in online illness communities. At the same time, the representatives of such a strategy did not participate in discussions, but

simply read forums of online communities without being their members. This use of online communities is marked by the representatives of the *monitoring strategy* as reluctance to engage in dialogue with other people; many of the representatives of the *monitoring strategy* prefer to remain silent and not to talk about their illness, they considered it unnecessary, and therefore tried not to participate in discussions on online forums:

«I'm just there, I'm reading various communities, that is, I'm just reading without any comments, I don't know any comments or participation, but sometimes it's useful and sometimes you can find a lot of good and necessary information there, but I'll say - so late» (participant 9)

That is, it is often important for the representatives of the strategy to read and receive the necessary information, but unlike the representatives of the *users strategy*, these participants did not consider it necessary or important to study the information in the forums and ask questions. The online community is something like a strategy for monitoring strategy «encyclopedias», as one of the participant once called the online illness community. That is, it is necessary to be able to read something and bring something out for yourself.

The representatives of the monitoring strategy have different backgrounds and different attitudes to life in rural areas, both positive and negative, and the spectrum of this ratio could vary significantly. But, the central line in the description of online communities and the use of the Internet is that it is important to use the potential of knowledge and the potential of accumulated experience which could be found and gained through participation in discussions and conversations in a community. The monitoring strategy representatives prefer not to integrate corporality and other aspects in the experience of chronic illnesses in the online sphere.

Conclusion and discussion

One of the most important aspects of the fluidity of online communities as a technology is the ability to communicate and get the necessary advice, but at the same time for the representatives of the monitoring strategy and for many representatives of the *communication strategy*, such communities do not contribute to recovery or quick treatment, but perform a completely different function - they facilitate communication and finding the necessary answers to questions, in some cases. Moreover, the forms of benefits generated by online communities can be excellent: for the representatives of the *communication strategy* such a benefit is the opportunity to communicate and the opportunity to share one's emotional state, for «users» such a benefit undoubtedly lies in the search for answers to questions in solving health problems, and for the representatives of the *monitoring strategy* such a benefit lies in the ability to observe and draw conclusions as they refer to the online community as an «encyclopedia» from which you can acquire the necessary knowledge for the treatment of the illness.

At the same time, the benefit and fluidity may differ. This is not a universal criterion for the usefulness of online communities for those residents of villages, in the Luga district of the Leningrad Region, who are using online communities. It's rather some kind of possible assessment I propose in this study, an assessment of the possibilities of online communities and at the same time their shortcomings, namely the shortcomings in the fact that they can produce lay knowledge and the degree of trust presented for various strategies for participating in online communities and have proved this fact.

Consequently, the trust in knowledge and the so-called unproven services, and advice on the basis of which it is possible to provide or not to provide necessary services in the future (credible goods), which are created in such illness communities if doctors participate in the forum discussions, indicates that the fluidity of such communities can be regarded both positively and negatively by users.

However, one of the important conclusions, in my opinion, at this stage of the study, is how older people translate rural life and the difficulties of rural life into online community spaces. This is largely determined by two strategies: the *communication strategy* and the *users strategy*. For the representatives of the *communication strategy*, the lack of communication and interactions in the rural community is transferred to the online space and, to some extent, the illness communities replace the village community exactly the opposite. That is, the village community, with the strong social connections and readiness to offer advice, is changing, the collectiveness is disappearing and not only advice is important, but rather the emotional and therapeutic support that the online illness community provides.

The representatives of the *monitoring strategy* use online communities rather as a tool in the treatment process. This tool is important and necessary because of the general dissatisfaction with doctors and medical incompetence in the countryside, even when it is possible to talk with neighbors or relatives and ask them for the necessary advice in the treatment of the illness. At the same time, lonely or not lonely living is an important factor in using online communities, which also determines the role such communities will play in the life of those with chronic illnesses. That is, current technologies of online communities offer many opportunities and provide many views on how you can manage your illness. Often for residents of rural areas, such management and the choice of the necessary method is perhaps the only opportunity to talk with someone or ask for the necessary advice on taking medications or changing the medication regimen in everyday life.

Another important aspect that deserves attention in the the future discussion are the features of corporality and the agency of their manifestations during communication and interactions in online communities. So, the representatives of the *communication strategy* are characterized by the preservation of their body and serious manipulations in treating the body in an offline communication space. Representation of the illness in online

communities becomes a kind of description of the complexity of experiencing a chronic illness and a stoic narrative of description. It is important for the *monitoring strategy* representatives when using online communities to transfer corporality to online communication, and here both the body and the agency of patients are represented and integrated into the communities themselves and into the communication that takes place in them and into the lay knowledge space where you can discuss different problems and read about different strategies and knowledge. At the same time, the body does not disappear here, but becomes one of the subjects of online interaction, i.e it is transmitted to the online space, which, of course, determines the features of communication and asking for advice in the community.

It is still too early to talk about the emerging online community as an actor in the treatment and life of chronic illnesses in older people, but at this stage, it can be noted that, together with the medications and doctors of the online community, those older people who use similar communities receive alternative views on the issue of treating their chronic illnesses. Another important component is the ability to analyze online communities from the point of view of the intended use, which differs among the representatives of the various strategies presented in this article. These research findings provide solid materials for reflection and further discussion.

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