

Characteristics of subjects with self reported history of psychosis who were interested in self-assessment of their functional status via online e-diaries

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Summary

Aim. To identify a profile of subjects with psychotic symptoms who were interested in self-monitoring of their functional status via an online electronic diary (e-diary).

Method. The TacyJakJa.pl website was promoted by means of a standard online advertising and positioning methods together with limited traditional advertising activities (an article in press, a radio broadcast). Physicians were not involved in recruitment process. Registered users of the website were offered a simple and convenient self-assessment tool to monitor their functional status in the form of e-diary. E-diaries were designed by psychiatrists for the purpose of self-assessment of mental state, everyday activities, therapy and treatment tolerability, in a registered users group.

Results. Over 18 months 450 individuals registered in the after psychotic crisis section of the website. Answering question of how did they found out about the website 86% of users pointed internet as the source of information, 8% – friends, 4% – their physician, 2% – the press. 70% of users, as they reported, were diagnosed with schizophrenia and paranoid disorders, 82% of them were hospitalized due to their condition. The group of users consisted mainly of people in their thirties, who completed their secondary education. 70% of them did not have paid job; majority of them were single (57% of women and as much as 77% of men; $p < 0.0001$). Despite significant life independence of users, as well as their understanding of the necessity of treatment (97% of registered users received outpatient psychiatric treatment), depressive mood was observed in the group. At registration the WHO-5 Well-being scale was completed by 239 subjects; and as much as 76% of them achieved total score below 13 ($\chi^2(239.1) = 65$, $p < 0.0001$), what indicates depressive mood and higher risk for developing clinical depression. There were no statistically significant differences between results of men and women.

Conclusions. Self-monitoring of functional status via e-diary generated a great deal of interest among younger users with psychotic experiences who received outpatient treatment, mostly singles, often with depressive mood. Self-assessment via e-diaries proved to be manageable and worthwhile. E-diary users were interested in active participation in their treatments, however without being encouraged by their physician, they discontinued regular self-assessment after several entries. Still, they visited other sections that the website, such as: ask a doctor corner, medical library, photo contests section, online chat rooms, and discussion forum they kept in touch, chatted and talked also with persons with no psychic disorders, who registered on the website.

schizophrenia / psychosis / self-assessment / guided self-management program for patients / online e-diaries / Health 2.0

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INTRODUCTION

The importance of the Internet as the source of medical and health-related information is growing and it is being used for more and more purposes. About 5% of all Google's search queries are related to health issues [1]. In 2003 Internet

users submitted approx. 12.5 million health-related queries per day, globally [2].

It is reasonable to expect that Internet's role as medical and health-related resources will grow further. This is relevant also in terms of mental health care, psychiatry, psychotherapy, psychic disorders and all the related areas.

Beside conventional and educational medical websites, which offer only one-way information, a new category was implemented several years ago – Health 2.0. type web services. The term was constructed analogically to the term Web 2.0. [1]. The key concept that lies behind Web 2.0 is participation, interaction and collaboration of all users in generating a website content. A concise definition of Health 2.0 is: the use of a specific set of Web tools (blogs, podcasts, tagging, search, wikis, etc) by actors in health care including doctors, patients, and scientists, using principles of open source and generation of content by users, and the power of networks in order to personalize health care, collaborate, and promote health education [3].

One of the consequences of this innovation is so-called patient empowerment. It is a situation when patients are encouraged to take active part in their own health management; they are provided with better access to valuable medical and health related information, they can develop deeper understanding of their disease state, health status and treatment plans; as a result they can make right decisions and choices regarding their physical and mental constitution. [4].

TacyJakJa.pl (SuchLikeMyself) [5] website was launched in 2008 and it was the first website that used Health 2.0. solutions in Poland. The website was developed by two women: a physician and a mathematician. In this paper we present results of 18-month pilot research project conducted between March 2010 and September 2011. The project was developed for self-assessment of subjects who underwent psychotic crisis. The project participants assessed their health status via online electronic diaries.

Users went through an anonymous registration procedure, filled in questionnaires and measurement scales included in an e-diary. It is important to point out that they made their own decision to join the program without any physicians' hints or recommendations.

TacyJakJa.pl is online educational platform dedicated to people with chronic conditions. The website gives them the opportunity to conduct self-assessment of their health status according to guidelines provided by physician (GSMP - Guided Self Management Program for Patients). This type of educational and therapeutic program is mainly addressed to patients with asthma [6, 7, 8] and diabetes [9]. However, some studies were undertaken to investigate its usefulness in psychiatric patients with affective disorders [10], and schizophrenia [11]. So far no analyzes have been published on such online programs for patient; and that is the key research subject of this paper.

TacyJakJa.pl website concept harks back to the US-based online service PatientsLikeMe.com. Polish version of the website is more focused on strengthening the cooperation with medical specialists and medical associations. Due to close collaboration between TacyJakJa.pl and medical professionals, the website represents high level of competency. Patients' medical questions are answered by medical specialists only. Other forum topics are monitored by medical professionals, too, in order to estimate their value e.g. we add comments to questionable therapeutic and health-related advices or we react to attempts to encourage other patients to stop taking their medicines and discontinue treatment without consulting their doctor.

TacyJakJa.pl website is HON Code certified (Health On the Net Foundation), which ensures reliable medical information. Also, it was listed on a government website (Polish Agency Of Business Initiative Development) www.web.gov.pl, as an example of e-Healthcare project.

Apart from administration of the website's content by medical professionals, another unique feature is the introduction of different types of electronic diaries for monitoring chronic diseases. These are simple questionnaires arranged by physicians or common scales authorized by its license holders (e.g. Asthma Control Test ACTTM in asthma or WHO-5 for overall wellbeing assessment). The importance of these e-diaries is not the value of a single survey filled on a particular day, but the observation of the change of dynamics and trends, which is the real information and benefit of the regular control of people's functional status.

User selected responses are recorded by the system in tables and/or graphs and they are printable in any date range. The benefit of their use is the possibility to observe trends and dynamics of health and wellbeing status change.

Patients, who do not fill e-diaries, are part of TacyJakJa.pl society mainly for discussion on forum and other reasons (i.e. chat, email). Those who actively discuss on forum are about 10% of all users (these data is confirmed by information from other social networks). The majority of people read the others' posts and are passive users of forum. It is worth to mention that reading questions addressed to Medical Consultant and their answers is a vital source of information for new users.

Patients, who experienced psychotic crisis read also posts in other sections, and sometimes even participate in discussions there – this way they learn about specific problems of those with other chronic diseases, like epilepsy or multiple sclerosis; and so they get themselves out of inner circle of people just like them. And vice versa, people registered in other sections learn some stories about patients after psychotic crisis; it helps them open up towards psychiatric patients and learn to accept them. Rubinka from asthma section says: "I understand them better now and my approach to them changed completely, in favour of course".

The website includes also „Entertainment and Fun" section, which is composed of quizzes, word games and posts (culinary recipes, music, travel and books), all proposed by users. Using those features of the site may be the first step in safe return to normal social life.

Signing up on the website is fully anonymous and free of charge. It is financed by sales of booklets and handbooks, sponsoring and paid surveys among portal users ordered by third parties.

THE CONTENT OF E-DIARIES OF PEOPLE AFTER PSYCHOTIC CRISIS

E-diaries for people after psychotic crisis were developed in cooperation with physicians specializing in community psychiatry from the Institute of Psychiatry and Neurology in Warsaw (dr. Katarzyna Prot, DM, Ph. D. and dr. Sławomir

Murawiec MD.PhD). The idea behind developing those diaries was to encourage people after psychotic crisis to monitor their functional status – everyday activities, on a regular basis, and also medication tolerance (possible side effects), then their emotional health. This project runs under the auspices of Community Psychiatry and Rehabilitation Section of Polish Psychiatric Society.

E-DIARIES FOR PATIENTS AFTER PSYCHOTIC CRISIS CONTAIN THE FOLLOWING ELEMENTS:

- *daily activities assessment*; questions about daily activities concerning 4 different areas, in 1 month perspective;
- *self care* (questions on self hygiene, shopping, cooking, managing house budget);
- *social life* (questions on relations with others, going out, conflict solving, ability to listen etc.)
- *physical activity* (questions on physical exercise, time management)
- *professional area* (questions on being systematic, target achievement, concentration)

Respondent can choose one out of five answers (1 – almost never, 2 – sometimes, 3 – often, 4 – almost always, 0 – not applicable (I don't want to answer)). Each answer corresponds to given number and color to make it easier to assess change in dynamics on screen or print. Color code makes it easier to assess at glance if a certain feature improves or worsens.

- *Wellbeing and emotional health self assessment*. WHO-5 point scale is used for the overall wellbeing assessment. When the result of an assessment is less than 13 points, the system would generate message advising to see physician.
- *The emotional health assessment* is based on a survey, which consists of 20 questions considering feelings, scored: 0 – no, 1 – rarely, 2 – often, 3 – most of the time, 4 – I cannot/I do not want to answer. Questions include: feeling of being observed, hearing voices, having commenting thoughts, influence on thinking, being stalked, sensing conspiracy, being in danger, intensity of feelings, being motivated to act, feelings of fear. This part of e-diary

is also color-coded, for easier trend observation, when printed.

- *Treatment and side effects.* Patients have the option to select drugs which are commonly used in psychiatry (in alphabetic order, by trade names; they also may add other drugs they may use (like contraception or antihypertensive) into it. The graph shows the name and an arrow indicating continuation of usage of the drug. Users may also select a symptom they consider a side effect and its severity (0 – not present, 1 – mild, 2 – moderate, 3 – fairly strong, 4 – severe). None of the drugs is directly linked to an adverse event, because patient's assessment would not be credible. Patients note drugs taken and separately select any possible unwanted symptoms, which they consider treatment related. Whenever there is a radical change of severity of adverse events (e.g. from mild to severe), the system displays additional message suggesting to contact their physician about a symptom exacerbation.

All the answers selected by patients in their e-diaries are automatically added into cumulative statistics. In every part of e-diaries description it is stressed that dynamics of changes and the trends are the real value, only when made regularly. The recommended frequency of e-diary completion is 4–8 weeks. User would receive an automated reminder by email during that time, when there is no data input. However, e-diary may be completed in any intervals.

There is number of advantages of completing online e-diaries, as opposed to paper ones: a paper diary may be lost or forgotten, the on-line one is accessible at all times wherever there is internet access.

the e-diary allows to make all sort of different notes, tidy graphs allow to look at one's disease from wider perspective and to observe certain relations or recurring events.

All the data from patients' e-diaries are automatically scored into cumulative statistics, which allows to compare the results against others.

The project's authors are aware that only certain group of patients (those who are familiar with computers) take advantage of using e-diaries, however their number grow year by year. Also on-line application is much more attractive for younger patients, and they constitute the majority of those who had psychotic episode.

SUBJECTS

In 18 months period (March 2010 – September 2011) 450 people registered in section named "After psychotic crisis". Regarding the source of information about the website, 86% learned about it from internet, 8% from a friend, only 4% from a physician, and 2% from a newspaper.

Women slightly predominate (52%) in the group who registered in section After Psychotic Crisis. By average, the users fit the following profile: typical user is 32 yrs old ($M=31.7$; $SD=11$), lives in a city (70% lives in cities with population above 30 thousands of inhabitants), with education not exciding high school degree. 35% declare university graduation, most of them are women (Tab. 1). Only 30% of patients have a paid job, 20% are students, the remaining 50% are kept by others or on a pension.

61% of users are single, 34% married or have partner, 5% are divorced. In the statistically sig-

Table 1. Level of education of users registered in section After Psychotic Crisis www.tacyjakja.pl

	Education ($\chi^2(2)=24$; $p<0.0001$)		
	primary	secondary	higher
Female	9 (4%)	122 (53%)	101 (43%)
Male	30 (14%)	132 (60%)	56 (26%)

There is usually one copy of a paper diary – the e-diary may be printed in chosen time range, and in any number of copies, e.g. one for physician, another for a family member or one's therapist.

There is usually limited space to make notes in paper diaries and they are not so clear to read;

nificant results ($\chi^2(3)=24$; $p<0.001$) men are definitely more often single then women (Tab. 2.) 62% of patients live with their parents, 24% with their spouse/partner, 12% alone and 2% in nursing homes / sheltered homes.

Table 2. Marital status of users registered in section After Psychotic Crisis www.tacyjakja.pl

	Marital status (Chi2(3)=24; p<0.0001)			
	single	divorced	married	in cohabitation
Female	120 (52%)	11 (5%)	68 (29%)	33 (14%)
Male	157 (72%)	10 (5%)	26 (12%)	25 (11%)

Registered users are mainly young people, 80% of women are under age of 30, and so 93% of men. At registration they declared being diagnosed with paranoid personality disorder and schizophrenia (70%), schizoaffective disorder (11%), delusional disorder (6%) and other diagnoses (13%).

In 52% of people the illness or disorder's onset was sudden, in 48% slow and increasing.

Most of users registered as patients after psychotic crisis have experienced hospitalization on a psychiatric ward (32% - once, 39% - 2-5 times, 8% - 6-10 times, 3% - more than 10 times). Only 18% of all were never treated in outpatients care.

At registration most of people completed the WHO-5 wellbeing index and their score was under 13 points out of max. 25, which indicates possibility of depression. 57 people (23.85%) got result ≥ 13 , 182 got under 13 points (Chi2(239.1)=65, $p < 0.0001$). These results are comparable in both groups of women and men.

People who complete e-diary on their own have also self-depended life and seem to manage everyday activities quite well, while being treated or consulted only in outpatients care.

As many as 90% people, are estimated taking care of themselves as good and very good, (the score was above half of maximum number of points).

In the area of social contacts self-assessment, more than half of the people registered as those after psychotic crisis (63%) consider their relations with others as correct (good), which means above the average score.

In questions regarding the active rest/time off the number of negative answer raises: 33% people consider their ability to organize free time and to be active below the maximum of possible score. Similarly, when it comes to estimating one's professional abilities, 31% people put themselves below the half of maximum score.

In the diary one may also put notes regarding their treatment effectiveness; the prominent group in that respect is second generation antipsychotics (58.4%). In this group 32.3% consist-

ed of olanzapine, 20% - quetiapine, 20% - risperidone and 58.3% - others (amongst which, as much as 24.6% of the whole second generation antipsychotics group was aripiprazole and 16% - amisulpride). Second, most abundant group of drugs (12.8%) was SSRI or SSNRI antidepressants, the third (8.2%) was the typical neuroleptics, the fourth (7.6%) - mood stabilizers. The remaining 13% were sedatives, hypnotics and antiparkinson drugs.

The analysis of results shows relatively good tolerance of treatment - the majority of people have not experienced the listed adverse events, or their severity was not high in the subjective assessment. Amongst medium severe and severe events women reported lack of concentration more often than men (29% vs 16%), sleepiness (22% vs 12%), sleep disturbance (21% vs 12%) and weight gain (28% vs 17%). For men, the most frequent problem was weight gain.

In diaries, the majority of patients evaluate their treatment positively:

83% - Yes, I believe that my drugs help me feel better

71% - Yes, I believe that my drugs help me in everyday life

98% - Yes, I want to continue my therapy

77% - Yes, I am convinced that my drugs prevent me from relapse

97% of registered users are treated by psychiatrist, 19% in individual psychotherapy, 4% participate in group therapy. Only 1.4% is under home care service, the same number participate in occupational therapy. 2% are members of self help groups and only 2 people use custodial care services.

DISCUSSION AND CONCLUSIONS

The website's users are relatively young, quite well educated people, as shown in the characteristics. They are compliant patients, howev-

er still quite depressive. What is interesting is that they consider their social relations as good, what may be really difficult for people with psychotic episode experience, as well in theory, as in clinical experience. TacyJakJa.pl website users, although often discontinue self assessment via e-diaries, remain on the portal mainly for discussion on forum and they also chat with people from other sections too (other diseases related). As the weakest side of their functional status, patients consider their professional abilities, even if they are well educated. It is significant that majority of them (70%) do not work at the moment, while they are young, self-reliant and compliant in their treatment. It points out to the area, which would require specific interest in intervention planning towards those who experienced psychosis.

Self-monitoring health condition by those after psychotic crisis by means of e-diary could be an interesting part of psycho-social interaction. The pilot program, based on ad-hoc registration of patients, who found an advertisement of the website on line, shows user friendly registration process and no problems with management of e-diary. Relatively low factor of continuation of regular submissions of e-diary (78% filled e-diary only 1-3 times) points out to finding better and more effective motivators, not only by website's doctors, but also by other doctors, for whom all cumulative data could become important input for the treatment, in-between visits.

Cumulative data of e-diaries can become a source of an insight for whole psychiatric community and an idea for planning treatment in accordance to GCP and healthcare policy.

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