

Which Social Inclusion for People with Psychiatric Disorders? Insights from the Web

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Abstract This paper describes a part of a need analysis carried out in the frame of a project financed from the ESF and aimed at training and work insertion of people with psychiatric disorders. In particular, the authors aim to understand if a deep study done through the Web can be useful in order to define the needs and expectations of people with psychiatric disorders and their relatives. As regards the methodological aspects, we have used the most common techniques for the analysis of big data: network analysis and web crawler. The results of the web study show not relevant differences with that derived from the traditional research. Evidence suggests that e-methods are useful for background analysis.

Keywords Network Analysis, Big Data, Social Inclusion, Mental Health

1. The Context: Psychiatric Disorders, Disability and Social Exclusion

As we read on the Global Health Observatory of World Health Organization¹, mental disorders are very common and costly for our Society, but the lack of trained human resources and of the infrastructures necessary to provide the services is a serious obstacle for access to the mere basic assistance. Data² show that each year, deaths by suicide³ are 800,000, compared with an allocation of resources equal to 2.8% of the health budget and one psychiatrist per 100,000 inhabitants⁴. In Italy, in 2012, hospitalizations for mental disorders -measured by the number of resignations- were 254,888⁵, of which 21.5% in day hospital and with a mean length of stay for inpatient equal to 14 days. In Liguria, in 2012, the days of hospitalization in Psychiatric Services for Diagnosis and Treatment were 56,716 for 108 beds and users of mental health care services⁶ amounted to 28,199 units, or 1.8% of residents [1].

The mental health disorders are certainly among the most disabling, as directly impact on our ability to interact

effectively with the environment around us, with other human beings and even with ourselves. It is not a coincidence that, in the ICF classification [2], mental functions are listed first, immediately followed by sensory and communicative functions⁷. The disability must always be understood as the result of a complex relationship between the conditions of the individual and the environmental factors [3]: its definition element is not embodied in a connotation of the subject, but in a wound produced on her/him by the characteristics of the context [4].

In a Society such as ours, which increasingly requires excellent performances, if an individual has performances considered inadequate and socially unacceptable, his personal identity is denied [5]. The person with a psychiatric disorder is object of processes of stigmatization⁸ and exclusion perhaps less obvious, but no less serious than in the past with his institutionalization in mental hospitals [6] [7]. It is a process of exclusion that is generated by the functioning - although reasonable and useful - of devices and apparatuses socially constructed: "the social inclusion is denied on a functional ground" [4].

As confirmed by the EU Policies and Regulations of the Structural Funds⁹ interventions aimed at promoting social inclusion and employment of people with disabilities are of crucial importance. In this respect, the two key regulatory references, in Italy, are the Law 328/2000 "Framework for the implementation of the Integrated System of

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Published online at <http://journal.sapub.org/ijpt>

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¹ WHO, http://www.who.int/gho/mental_health/en/.

² http://www.who.int/mental_health/prevention/suicide/suicideprevent/en/.

³ Mental illnesses together with alcohol abuse is a major risk factor for suicide.

⁴ In the 85 countries considered.

⁵ Source: Istat, <http://dati.istat.it/>. With a resignation rate equal to 428.1 per 100 thousand inhabitants.

⁶ Mental health centers (91%), residential (5,4%) and semi-residential (3,6%) services.

⁷ With its body structures.

⁸ And self-stigmatization by the same person with a disability.

⁹ In the Article 9 of the EU Regulation 1303/2013 (European Parliament and Council) on the Structural Funds and the European Investment Funds, one of the thematic objectives is "promoting social inclusion and combating poverty and discrimination".

Interventions and Social Services” and the Law 68/1999 “Regulations for the Right to Work of Disabled”. The first one says, among other things, that “the subjects... with total or partial inability to meet their own needs for physical and mental disabilities, with difficulty of insertion in the active social life and in the labor market... have priority access to services and benefits provided by the integrated system of interventions and social services” (art. 2 par. 3). The second one aims “to promote inclusion and integration of disabled persons ... through support services and targeted employment” and applies among other things “to people of working age suffering from physical, mental or sensory and handicapped intellectual” (art. 1 par. 1). In this framework, the social and health services and employment services cooperate in the rehabilitation and inclusion of these people according to the principle of integration, despite significant institutional constraints and a chronic lack of resources. Also the cited European Funds -in particular the European Social Fund- are used to finance these interventions according to a principle of vertical subsidiarity.

1.1. An answer at Local Level: The Project **MentealLavoro - Laboratorialmente**

Within a framework of social and employment emergency [8], which strongly impairs the chances of social inclusion of the most vulnerable (and beyond), the Liguria Region has promoted, with the call “All Skills at the Centre”¹⁰, the creation of a series of initiatives aimed at the social and labor inclusion of disadvantaged groups.

Among the projects approved and funded was “MentealLavoro: Laboratorialmente”. It was an action directed at users with psychiatric disorder of medium-to-medium-severe level, requiring for the employment paths very gradual, allowing the person to mature the transversal and specific skills required in an environment very similar to that in which could be inserted in the future, but at least in part protected. The partnership¹¹ reflected the principles of socio-health integration and networking that should characterize this type of initiative. The project included several actions: analysis of users and their families’ needs, training workshops and work experiences, training and information activities for families, training of operators, awareness of the corporate world and networking, monitoring and evaluation. The DISFOR was in charge of both the first and the last of the above actions.

¹⁰ D.G.R. 75/2012 “Call for projects aimed at the realization of integrated interventions to promote the social and labor inclusion of those at risk of social exclusion – All Skills at the Centre” out of the OP CRO European Social Fund Liguria Region 2007-2013 Axis III Social Inclusion.

¹¹ Internal partners: Italian Women's Centre Foundation Training, Local Health 3 Genovese, Ligurian Association of Families of Psychiatric Patients, University of Genoa - Department of Education (DISFOR), Federation Regional Solidarity and Labour, ATS Quadrifoglio and other social cooperatives. External partners: Office for Social Inclusion and Work Placement of Disabled Persons of the Province of Genoa and the Office of Coordination Employment Integration of the City of Genoa.

2. What Resources on the Web for People with Psychiatric Disorder? The Adopted Methodology

Given the many aspects that characterize the project “MentealLavoro”, we decided to contextualize the dynamics that exist today on the web regarding the needs of people with psychiatric disorder. The results and the considerations that we will present below are just a small part of a larger research design, aimed to analyze the needs of users and families, monitor the progress of the project and evaluate it.

As for the reasons that led us to conduct a preliminary investigation on the needs of people with psychiatric disorder in this perspective, we felt it was useful to analyze what is happening in the network, thanks to the support of internet studies, focusing on the networks relations arising in Web 2.0 environments. Multimedia, hypertext, but above all the interactivity and digitization that distinguish digital media by new media [9] allow us to have access to a multitude of data arising from below, and without any kind of intervention the researcher.

Complex social networks are very relevant in our Society, especially in a period in which technological development plays an important role [10]. When we discuss social networks, we cannot do without think of the Web, which is not just a showcase of information, but a virtual space in which to create participation between the different nodes that make up a dense network of relationships [11].

The nodes composing the social network that we are discussing are not only people, but also organizations, newspaper articles, towns, neighborhoods, roles within organizations and even, as in the case of study, web pages [12].

By Web 2.0, we cannot only make an ethnographic research with the support of Discourse Analysis, but also rebuilding, thanks to Network Analysis, the relationships that develop between the nodes.

In this regard, we found it useful to make two insights: first, in a macro social perspective, through the mapping of Web sites with higher level of consultation and, secondly, looking at the micro social dynamics, focusing on a Facebook group. The choice of these two insights flows from the recognition that they are the users themselves to select the Facebook page or the site to see. The classical conception, according to which are the media that relate to the person, overturns and opens the way for a social actor who decides in the first person to what sites and social networks wants orientate [13].

Ethnographic studies in 2.0 environments can reveal or not the research activities conducted: in our case, it was not a participating observation; we just monitored a Facebook page that had the most active and has the largest number of people registered. Hence, we went beyond with the Network Analysis, playing an ego-centered study. This analysis allowed us to sense the level of participation within a virtual space.

The network allows us to tap into a considerable amount

of data stored that today we exploit only in small part. As to the procedural aspect, once concluded the selection phase of online sources, we monitored and collected data through special crawling software, post and hashtag. After that and in addition to the Network Analysis, we made also a Discourse Analysis [14], only possible thanks to Big Data available on the web through which to realize mixed-methods between online and offline techniques [15].

About the deepening performed on the web, the hashtag #psichiatria¹² resulted particularly discussed: many were the big data available; it was possible to analyze about twenty of Facebook groups of family members and professionals and as many of Twitter hashtags, while tumblelogs were about thirty.

3. Surfing the Network between Different Everyday Scenarios: Search Results

We enter into the merits of the findings. The first analysis conducted has allowed us to highlight the macro trends currently existing on the web regarding the hashtag #psichiatria, with particular reference to laws, rights and perception of quality of life for people with psychiatric disorders. In this regard, given that our attention is oriented towards a first analysis of the context, looking for the tools to a cross reading of the studied phenomenon, we decided to investigate at first the Italian web pages.

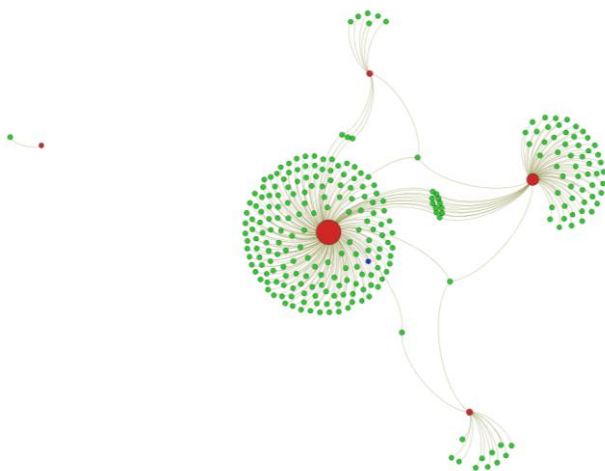


Figure 1. Mapping websites #psichiatria

Always in the past, the web has played a role of mass media information: in its earliest stages of development, the sites were limited to providing a showcase of the services offered to users. Today, thanks to the web 2.0, the mode of use of the network has changed, as well as the software for the analysis of the network. In Figure 1, we represent the product of an analysis carried out with a specific mapping software of web pages: it emerges a reality rather

articulated and complex, where are depicted 265 sites, with high level of consultation.

By mapping the links, four clusters are recognizable: a first that highlights the most popular blog, a second concerning the rights of people with psychiatric disorder, a third in which there are web pages that deal with medical and scientific information and, finally, a fourth of a divulging journalism.

The four “bridge nodes” between a cluster and the other, which in the figure are recognizable since larger and visually central to the group of interest, are the pages with greater numbers of access and from which begins the consultation: these nodes seem the median strip of a flow of information distributed randomly. No coincidence, these sites are well organized within them, providing the user with a large area of suggestions to as many specific links.

As for the contents of the four groups identified, blogs are more numerous than the other sites. Heterogeneous with each other, some are born as “rib” of national information sites, others spring from will of family members of people with psychiatric disorder, a few others directly from the initiative of those directly involved. What they have in common are the information found: general news about the new scientific discoveries, comments referring to the social stigma, daily difficulties, considerations about “the diversity” and the debilitating character of the disease both for themselves and for the loved ones. In a few cases a proactive interpretative key is adopted, while often there is a general sense of inadequacy in living the everyday life.

The second group includes the websites that deal with disseminating and protecting the rights of people with psychiatric disorders: these are for most web pages that put the surfer aware of existing legislation in Italy, and where are accessible areas dedicated to online discussions with psychiatric experts, psychologists, career counselors, doctors, etc. The function of these web pages is especially orienting and information.

In the third group are very technical medical and scientific sites, mainly addressed to professionals, medical specialists and health professionals. Finally, in the fourth group are the websites of journalistic investigation, which usually you log because posted directly from the blog.

Until now, we have indicated the guidelines of surfing the Web regarding the hashtag #psichiatria, but we missed the point of view of the individual social actor. We have thought to fill this gap by placing attention to what happens within the social networks, starting from the network above described. The mapping of the sites revealed a central page - “stop opg.it” - from which originate many ramifications to other nodes and to other clusters: we therefore decided to analyze the Facebook page of this site and to deepen the ego-centered relationships starting from this.

The Facebook group in question has 1,231 members at the time of the analysis: this is an aspect to underline also considered that, by monitoring the group, the level of

¹² In Italian.

participation is high and number of members is growing¹³. The network that emerges is composed by 330 nodes and 518 ties: a tight mesh, where many participants exchange comments with a high level of interaction: there are many likes that in the figure below are denoted by different colors, while the relative size of the nodes distinguishes the most discussed conversations.

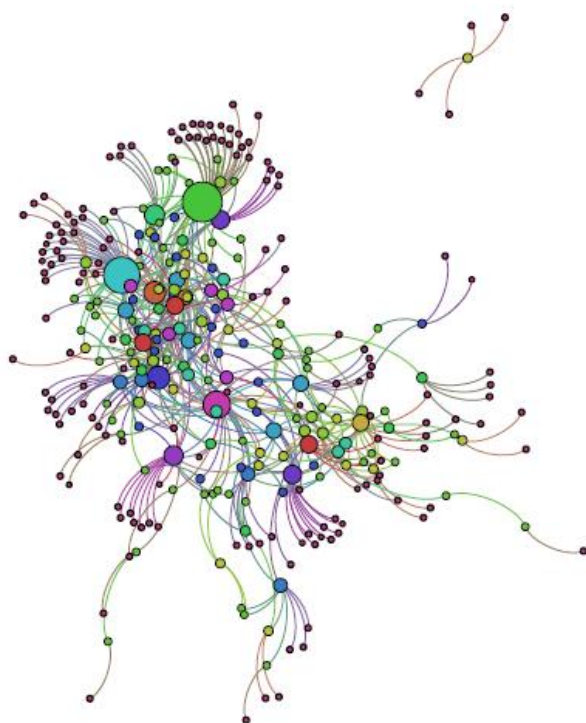


Figure 2. Ego-network of the Facebook page “stop opg”

The main categories emerged from the analysis of likes - the consensus expressed by users - are traceable to a well defined shortlist of themes: the “after us” (35%) is a deeply felt issue for family members, worried by the advance of years and the needs of their loved ones when they can no longer support them. The discussions concerning the exchange of information on civil rights (30%) have the attention of many, as the debate regarding employment (14%), the activities to be performed during leisure time (13%) and the self-esteem (8%). Women are the main users of the page and to the extent of 47% are of Italian nationality.

Not surprisingly, in our opinion, emerge arguments very similar to those contained in the website¹⁴, highlighting the role that Facebook groups hold among social networks: they are a free space where you can discuss with similar people with no filters, if not those concerning the netiquette to be adopted across all social media.

4. Conclusions Remarks

The dimensions related to autonomy and social and

working inclusion appear as crucial so that people with psychiatric disorder may gain greater awareness of themselves and define their identity within the Society. This is demonstrated repeatedly both in social networks, blogs and forums, both from the needs analysis carried out in the social health district of Genoa. The economic purpose of the work - although always present especially in a time of crisis such as the current - loses part of its importance in favor of the relational and social recognition, where to relate with the other becomes the time for the definition of the self. Collaterally emerges a series of needs that are closely linked to the autonomy of working: the home, the specific skills, psychiatric support, etc.

We tried to highlight how investigations conducted through social media may contribute as background analysis; they do not define the boundaries of the research, but deepen the discussions born between unrelated, who have no ties to of any kind other than similar problems and needs and therefore a common imaginary. Network Analysis allowed us to contextualize the most relevant aspects of the needs. Web 2.0 allowed us to identify indicators that could be used with traditional tools (focus groups, brainstorming, face to face interviews). We also report particularistic mechanisms of self-representation that indicate a common thought, expressed in front of a digital audience [16]. These aspects are well matched with the concept of medicalization [17]: where the care can no longer be thought of only as an act of compliance, but rather linked to an overall well-being of the person. Where the cure, i.e. the Medical management, is a concept now nuanced and partly overcome by the care, which is the idea of caring in the most general sense also taking into account the daily life of the person [18].

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¹³ After six months, the members are 1,535 (+25%).

¹⁴ <http://www.stopopg.it/>.

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