

Patients and carers involvement: Methodologies and experiences in the forensic system.

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Abstract

The involvement of the patients inside the forensic institutions can have an added value for enhancing the efficacy of the treatments, improving the Quality of Life for patients and make lesser their length avoiding the long stayer. The Cost Action IS1302 has developed a special goal for Patient Involvement and at the end of the 4 year Action it was held a Training School on this issue. The main techniques and methodology for patient Involvement (Rehabilitation, Advocacy, Recovery) are described and analyzed and collected the paper of the experiences in forensic Institution in Europe. The component of the Training School elaborated a paper with recommendations for achieving the target of Patient Involvement in Forensic treatment.

Keywords: Patient involvement, cost action, rehabilitation, recovery, advocacy.

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Introduction

The treatment of psychiatric patients in forensic institutions has the characteristic of being compulsory and is mainly defined by judicial orders. This means that it may be very difficult to acquire the consensus of the patients to undergo treatment and to take an active part in their own therapy and rehabilitative plan. Patients not adhering to their treatment and feeling uncertain about their future and their rights, represent critical factors for “long stays” in forensic institutions: they can remain “stuck” in the system for a long time without moving towards community treatment or a less intensive security level. It is possible to increase patient’s compliance by working to involve them in the planning of the treatment: the goal is to help them to recover their abilities that could be utilized, after discharge from the forensic facilities, in a social environment. The experiences and practices of patient involvement in Forensic Services are scarce: a systematic review, by Eidhammer et al. showed that there is barely any research regarding the clinical effect of the patient involvement approach on violence risk management in forensic mental health practice. The authors suggest that clinicians may learn from positive experiences concerning user involvement in general psychiatry and carefully adapt them and test them out in the forensic treatment context [1].

Meehan et al. interviewed 27 patients in a high security setting on perceptions of violent behavior. The cause of aggressive behavior centered around five major themes: one was the lack of patient-centered attention. Social and organizational factors need to be addressed to change the punitive subculture inherent in forensic psychiatric facilities, and to ensure a balance between security and effective therapy [2].

Cost action IS1302: Working group on patient involvement

The COST Program of the European Union is a networking instrument for researchers, engineers and scholars aimed at cooperating and coordinating nationally funded research activities. The COST Action IS1302, aimed at creating a network of research of forensic systems, has defined a special goal directed at patient involvement, ex users, family members or other Associations who are interested, or who are currently working, in the forensic field and have the objective of improving the quality of life in Institutions [3]. During the 4 years, from 2013 to 2017, the Action IS1302 developed a wide range of activities concerning Patient Involvement:

a) A survey was carried out aimed at discovering patient associations, carers, relatives, or any other organizations currently working for patient rights.

b) A questionnaire was sent to the participant members of the Action to obtain best practices for treatment of forensic patients, mainly in countries that have the problem of long stays.

c) Two active people were invited to have a talk for the meetings and the conferences of the Action: the first one, from the Netherlands, was an user of the forensic services and he is currently working as advisor in a mental health hospital; the second one, from the United Kingdom, is a caregiver and works in a Forensic Institute.

d) Two short term Scientific Missions aimed at identifying in the forensic facilities the best practices that work for patients discharge. The two countries visited were the Netherlands and the United Kingdom.

e) One of the final results of the Action was the database that assembles the main organizations working inside forensic

facilities of various countries. A future goal could be to create a network of the main, or most active, organizations that could be involved in future activities or projects.

f) At the end of the Action, May 2017, a Training School focusing on patients and carers involvement, and participation, in long term Forensic Facilities, was organized and held in Brussels.

The Training School deepened the knowledge of the basic concepts of the importance of implementing Patient Involvement in Forensic Facilities, by using the methodologies and the techniques widely adopted in many Health Systems.

Rehabilitation programs: The psychiatric rehabilitation promotes the recovery of patients, a full community integration and an improved quality of life for people who have been diagnosed with any mental health condition that seriously impairs their ability to lead a meaningful life [4]. Psychiatric rehabilitation services are collaborative, person-directed and individualized. Psychiatric rehabilitation is a mental health practice, specifically for outpatients, that can take place in a wide variety of settings, community-based or residential [5]. Patient-Centered Care: the users are the focal point of the care system, not their illness. They have the maximum priority and attention. By shifting the focus away from the disease and back to the patients and their family, it is possible to improve the quality of care and its effectiveness. The Shared Decision Making helps people, who have experienced an illness, to receive the best treatment and guarantees the best perception of care [6]. It is necessary to modify the way that services and organizations work, and finally to engage families and communities in the delivery of health care [7].

Recovery: The Recovery phase is a process of change through which individuals improve their health and wellbeing, live a self-directed life and strive to reach their full potential [8]. According to these principles, the recovery process of the patients must be self-directed, strength based, individualized and person-centered, following a holistic goal. The Recovery approach benefits from the empowerment of the person, restoring hope and responsibility and guaranteeing respect. Gillian et al. explored perceptions, experiences and meanings of recovery in mentally disordered offenders and their conclusion was that for this category of patients the basic concepts of recovery such as hope, self-acceptance and autonomy appear to be less meaningful, compared to medication and psychological treatment, and relationships with staff. The conclusion was that the recovery approach needs to be modified to be used in forensic psychiatric services [9]. Drennan and Woolridge in 2014 underlined the importance of recovery principles and practices in forensic mental health services, attaching importance to relationships between professionals and service users and the potential of peer support [10,11]. Bradley Mann, Elizabeth Matias and Jo Allen, argued that the recovery approach does overlap with elements of forensic practice, in terms of its emphasis on promoting greater responsibility and control [12].

Advocacy: Advocacy is an important vehicle for the raise of the awareness on mental health issues and ensuring that mental health is on the national agenda of governments. Advocacy can lead to improvements in policy, legislation and service

development. The concept of mental health advocacy has been developed to promote human rights of people with mental health disorders, reduce stigma and discrimination. It consists of various actions aimed at changing the major structural and attitudinal barriers and achieving positive mental health outcomes in the population. The stigma regarding mentally disordered offenders is particularly evident, due to fact that they are still considered dangerous on account of their violent behavior in the past, and this issue implies a risk of recidivism. Advocacy can help users and families to express their opinions and influence policy makers, attempting to change policies and mental health legislation, also in the forensic field, and improving quality of services. Advocates for people with mental disorders will need to clarify and collaborate on their messages [13].

The participants of the Training School have also discussed the Nice (National Institute for Health and Care Excellence) Guidelines of 2015 on Violence and Aggression Management [14] the guidelines consider that violence can be prevented by involving service users in decision-making regarding their care, and jointly developing care and risk management plans. The guidelines propose that in any setting in which restrictive interventions could be used, health and social care provider organizations should train staff to understand and apply the Human Rights Act. This training should enable staff to develop a person-centered, value-based, approach to care, in which personal relationships, continuity of care and a positive approach to promoting health underpin the therapeutic relationship. An understanding of the relationship between mental health problems and the risk of violence and aggression can help to prevent it.

Results of working groups on patient involvement

At the end of the Training School the participants, psychiatrists, psychologists and ex users, drew up a paper containing recommendations to be included inside the final report of the Action IS1302 with the aim of bringing these issues to the attention of the people responsible for the Forensic System. The main suggestions of the paper were:

Knowledge of individual rights

It is extremely important to work on the knowledge of users' rights. Every single patient in a forensic facility is on compulsory treatment: the treatment concerns their person so every patient should be made more responsible for exercising their rights and checking the treatment they receive. The knowledge of the individual rights should be delivered at the moment of admission by independent parties, better if they are external people to the facility or service, not by the psychiatrists or the staff in general [15].

Patient autonomy

The patients must be encouraged to take care of themselves and the environment, they must be able to manage their own money and develop their social abilities, both relational and affective. They shouldn't become dependent upon the institutions they live in (in terms of care, staff support and social welfare). Staff must work on making them independent and autonomous, adopting proactive interventions [16].

Improving the person-centered care plan

The client is at the centre of the treatment plan. They are the owner of the care plan and this is why they should be involved in using Shared Decision Making. The staff of the facilities

should encourage them to be aware of the basic principles of their treatment so they can be careful for themselves [6].

Encouraging patient groups

The users must be encouraged to take care of others, so that they can understand that they are also able to take care of themselves. Regular meetings between patients and ward staff can help to produce a sense of belonging. They are forced to live in the facility for a long time and, consequently, this period of life must have a purpose, something that gives them a sense of utility and participation [17].

Connection

People under restrictive measures should be encouraged to stay connected. They shouldn't run the risk of losing connection with their life, their relationship, their environment, their affection and family values, and any other aspect that can give sense to their life. Only the patient can choose, if there is no risk to others, the significant relationships and interests that give them a life that is worth to live. The patients must increase, and not have the risk to lose, the sense of belonging to a community.

Peer support

Peer support is the most powerful method to improve autonomy and share knowledge and emotions among people who have similar experiences. Peer Support helps people to remember that there's hope: "*if my colleague was able to do this it means that I can also do it by myself*". Peer Support also helps to fight against stigma: regular groups of peers can prove how mental health people in forensic Institutions are able to engage themselves in doing self-managed social activities and show an acknowledged feature of the forensic population [18].

Make patient involvement an indicator of quality

Every facility, or every clinic having several forensic wards, should have a protocol in the Quality Management System that foresees regular meetings between patients, or between staff and patients, and promotes peer support. The Involvement of the patients should be considered an excellence and a quality indicator.

Participation of relatives and carers

Staff and Managers of the facilities and clinics should schedule regular meetings with the families and civil society. The staff, or selected members, should meet family members and teach them the basic concepts of correct behavior when living with a patient. It is necessary to give them attention and listen to their requests for support and help. Psycho-education for both patients and their close relatives is essential when the Care Plan foresees an eventual return to family life. It is particularly important to stimulate the involvement of the social network of the voluntary association and charities, that can support families, before and after the discharge of the patients [19].

Clinic policies

The Clinic should weave relationships with other Institutions. This helps to acquire faith in the clinic's work and their goals, it could improve a sense of security for citizens

and local institutions and, last but not least, it could help to look for new opportunities for outpatients (jobs, education, culture, participation in social life). For example, patients can do voluntary work for charities or other institutions. Patients could have a perception of themselves as "bad people", due to the offenses they caused in the past, but working to help others (refugees, poor and other needy people) they are also helping themselves.

Leave something to society

Working to build or restore something for the community, as a kind of restorative justice, can give patients a sense of importance for their role and presence in the local community.

Empowerment and advocacy

Every patient must discover his/her own strengths. They can have the opportunity to learn and discover hidden or lost abilities. They should be able to make informed decisions about their lives and positive outcomes to reach. Empowerment of the capacity is the most powerful factor to improve the quality of life and participation in social environment.

Struggle against stigma

Stigma is probably the main factor that causes people's mental illness to become chronic; bad opinions and prejudice have a negative impact on people's mental health, making them lose connections and hope, throwing them into the chasm of hopelessness [20]. The struggle against "stigma" is the main target and goal of the World Health Organization's policies [21]. Periodical openings of the facilities to public meetings or Conferences, planned by the clinic or the Facilities, followed by actions that involve the active presence and contribution of the patients, should be provided. The fight against stigma could benefit from periodical clinic "Open Days" (avoiding anyway that they could have a resemblance to a visit to the "zoo").

Information management

Correct and loyal relationships with the media help to give the correct information and help people to have a sense of security. News can be blown up out of proportion, stressing the bad points, instead of simply informing people about what really happened [22-25]. It is good to have contacts with schools and adolescents, so that they can understand that patients are not rejected by society but are still part of it.

Staff identity

Sometimes the staff of a Forensic Institution don't really know what is asked of them. Who is the final client? The Society? The patient? The legal system? This uncertain role makes them loose, or weaken, their identity and the role they have in the system. Should the staff protect and take care of the patients or should they defend social safety? Or both? Professionals and staff must be strong minded and they have to be sure that their primary objective is the care of the patients. Only a good care can create the conditions for lower risks. "I don't like your past behavior, but it doesn't mean I'm rejecting you as a person". Professionals should always remember that the patient is the centre of their work, not society, punishment or the legal system.

Conclusion

The incarceration or the hospitalization, by themselves, do little to interrupt the vicious circle of mental illnesses and criminal behavior, mainly for those ones who have comorbidity with drug abuse that can make the offenses more frequent or serious (22,23,24). Mentally ill offenders sentenced to incarceration, hospitalization, security measures, exhibit a high rate of recidivism, once they are discharged, and sometimes the relapse into crime seems to be more dangerous. Punitive models without rehabilitation do not solve underlying issues (25,26). The policies on treatment of forensic patients need therefore to face a radical change: it is needed to look for innovative methods and programs. The basic principle should be: “to work *with* the person” and not “*on* the person”. There is no wellbeing without good mental health and we have the duty to perceive the mental health of the person (27,28). The discussion on the utility of the recovery in forensic services implies the acceptance of ethical principles that forensic psychiatrists don't seem to share, mainly for very dangerous people (29). A double stigma hits people in forensic institutions.

- They are mentally unwell.
- They have committed crimes that may have received media attention.

This means for staff dual responsibility:

The first responsibility is to support the patients to get better;

The second one it to protect the society and other people.

Staff may choose to pay less attention to patient rights, due to the risk of recidivism and violence they could act on discharge or during the treatment. So the need for security could win versus the work for care and rehabilitation. Can patient involvement increase risks for staff and other patients in the facilities? Can patient involvement cause a higher rate of recidivism? Namely, changes in the organization, more autonomy inside the facilities and wards, may enhance the risk of violence and let discharge very dangerous patients before their time. On the other hand, patient involvement aims at reducing self-harm, the number of long stays, and can help patients to acquire a better quality of life and respect for their human rights. A careful and in-depth evaluation of the individual risk factors can help staff to avoid that psychopaths, or people with antisocial disorders, can take advantages of the trustful climate in the ward (30).

Last but not least, by improving patient involvement, it is possible to reduce the cost of the system because the institutional treatments are expensive due to the high costs of security tools. The integration of the principles of patient-centered care into service delivery in forensic mental health hospitals can help to have better results (21). The success of the treatment is seen as a dynamic process materializing across many different domains in the context of the FMH system, and not only on diminution of reoffending (31). At the end a comprehensive model of patient involvement has to be used in Mental Health Care (32) and this should be done for forensic patients too. This model can serve as a guide for policy makers and field workers to shape policies to stimulate involvement. As a final consideration, the members of the Training School shared the conclusion that advocacy, recovery, rehabilitation can help forensic patients to

change their attitudes to violence and bring to the result of less recidivism at last. They proposed, for a final key concept, this sentence: “Involvement means traveling together, so every trip is a discovery: at the end of the journey the patients can discover their individual recovery”.

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