

The patient's view on issues of safety and mental illness

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The patient's view on issues of safety and mental illness

People with mental illness caught between a rock and a hard place

Irene Geerts

presentation for Cultural Perceptions of Safety, 21 Jan 2021

Wherever you are, you might recognize this: when a violent crime is committed, society is always shocked, but perhaps most of all when the perpetrator has a mental illness.

This is how it usually goes here: The public is outraged and points out the stereotypical link between mental illness and violent behaviour: How can it be that the safety of the community was so jeopardized when it was a known fact that the perpetrator was mentally ill?

In these situations, over the past decades, communities who feel unsafe often have found themselves head to head with authorities and mental health professionals, protecting the personal safety of people with mental illness as, they say, they are instructed to do by the law.

But what is the position of the main character, in all this, the psychiatric patient? And of course I am aware that my using the term psychiatric patient here is not unproblematic. But I do it to link my story today to Roy Porter's seminal article "The patient's view", a compelling plea from 1985 for a medical history from the perspective of the person suffering from illness. This perspective, however, is still remarkably rare in medical history, as it is in the historical debate on safety and mental illness.

That is why today I want to zoom in on the patients view by taking you back to a very sad case from the 1990s: a 12-year old schoolgirl murdered in the street by a neighbour who was known to be a psychiatric patient with violent tendencies. This case led to such an intense public debate on safety that it would mark a shift in positions in it, notably in the position of the clients' movement.

I will first introduce you to the situation in Dutch psychiatry up to that fatal moment in 1993. Then I show you how the case of the schoolgirl was debated in terms of safety, using newspaper and television sources, to give you an insight in the opinions of all parties involved, boiling down to the patient's view in all this.

1 Historical background

Up until around 1970, in The Netherlands as well as in other Western countries, it was considered in the interest of people with mental illness as well as in the interest of public safety to have them admitted to mental hospitals, whether they wanted to or not.

Inspired by critical thinkers who framed such institutions as instruments of the state to discipline the people, the anti-psychiatry movement started spreading the idea that isolating psychiatric patients far away from the community was not in their best interests at all; instead, it was damaging and stigmatising.

Progressive mental health professionals promoting these ideas in The Netherlands were soon joined by the emancipation movement of psychiatric patients, united in the *Cliëntenbond* or Clients' League in 1971.

They made public how in many institutions psychiatric patients suffered from a lack of proper care and even abuse.

Number 1 on their agenda was the patients' legal position.

Under the Dutch Insanity Act, that dated from 1884, people could easily be held in institutions for years against their will, on the grounds that they were dangerous to themselves or others, or simply because a doctor thought it was in their best interest. Over the 1970s and 80s, a new law was negotiated. Someone's best interest was no longer a ground for forced admission, and endangering themselves or others could only be a ground when it was very serious.

Parallel to that legal development, there was the development of "deinstitutionalisation", which meant that the number of beds in mental hospitals was significantly reduced. The ideal behind this was that people with mental health problems should have their rightful place in society like any other citizen and live in communities like everyone else, supported with extramural care and community facilities. Putting an end to stigmatisation and exclusion in this way would be in the interest of the personal safety of people with mental illness and the public safety of the community, for any citizen could become mentally ill. The goal was a better society: a society in which there was tolerance for all kinds of people.

2 Case

These were the law and the policy on that fatal day in March 1993. 12-year old Zülbiye Gündüz was walking to school in Amsterdam when she passed her downstairs neighbour Rob V. on the street. Rob suffered from schizophrenia and was notorious for his aggressive behaviour. Requests from neighbours to authorities to do something about that, had fallen on deaf ears. Just before Zülbiye came down that morning, Rob had left his downstairs apartment in an agitated state. Outside, he had picked up a table leg from the garbage left on the pavement and already threatened two people with it when Zülbiye caught his eye. She died in the ambulance that rushed her to the hospital.

3 The debate in the media

That same day Zülbiye's murder was all over the news. Her family and neighbours were outraged of course: If this man was sick in the head, why had he not been locked up in a psychiatric hospital, even if that was against his will?

The police pointed out that "as long as there was no blood", according to the law, they could not intervene.

Mental health care professionals were even more explicit: they stressed that it was in everybody's interest that it was legally impossible for citizens to report each other and have each other locked away.

A remarkable voice in the media was that of the parents of people with schizophrenia and their association called Ypsilon.

They pointed out that what mental health workers saw as personal safety for psychiatric patients, respecting their autonomy even in times of crisis, was in fact exactly the opposite. People undergoing a psychosis, the parents explained, do not feel there is something wrong with them, so they will not ask for help. But respecting that, which meant not offering them help either, made them extremely vulnerable, as the psychosis could escalate without treatment or care.

What was more, the promised expansion of extramural care and facilities had not happened for lack of money, so it was not even much help on offer.

As a result, these parents saw their children perish in their apartments, hiding from the world that was too much for them; or ending up homeless and abused.

"People are dying the streets!" the president of the Ypsilon parents association exclaimed on tv, and she did not exaggerate.

Several cases of homeless people freezing to death outside on a cold night made the news in those years.

And so did the case of a schizophrenic man who lived completely isolated in his flat in Eindhoven. Three neighbours had forced themselves in and tortured him to death – among other things, by hitting him with a table leg.

A retired psychiatrist agreed with the family association and said that in 20 years time we would look back on this situation in shame. According to him, mental health professionals interpreted the law in a way that was too narrow, the law did allow forced admission sooner. But this was an unconventional approach at that point in time.

4 So how did the patients look at this?

They are remarkably rare in the media sources, but they are there and one event in particular sheds an interesting light on the matter. A year after the death of Zulbiye, the Clients League organised a panel discussion on the question whether the new law and the way it was interpreted went too far in protecting the rights of the psychiatric patient.

No, was the voice of its members, coming from the audience. A psychiatric hospital is like a concentration camp, someone remarked - that was a classic image in these circles.

Many Clients League members associated forced admission with undergoing electroshocks against their will and being locked up in isolation cells without any perspective or support - horrors that the League had fought against since it was formed in 1971.

But there was also a new voice on that panel in 1994: Maarten Vermeulen, who had also experienced psychosis first hand. He was the chairman of a brand new association for people with schizophrenia, called Anoksis.

He felt strongly that the new law was not at all in their interest. Like the family members, he associated the autonomy as it was interpreted in the application of the law with leaving a person in psychosis to their own devices to perish in lonely room or under a bridge, in rags, with only a shopping cart with personal possessions.

In the following years, the interpretation of personal safety of people with severe mental illness voiced by the Anoksis chairman would take precedence over the definition of the Clients League that had been dominant for over twenty years. Mental health workers increasingly interpreted the law more broadly, carefully putting some boundaries on the autonomy ideal. In 1996 they were even urged to do so explicitly by state secretary of Health Erica Terpstra.

Conclusion

The murder of Zulbiye in 1993 was so shocking to everybody that it became hard to hold on to the interpretation of the law that put the autonomy of the patient above all else. The Clients League and the professionals inspired by anti-psychiatry had been successful in putting their position central: the position that ruthless autonomy was in the best interest of the personal safety the patient, even if that meant living an isolated, stigmatised, difficult life in the community.

The murder of an unquestionably innocent child created space for another position: that of the right to receive care when the illness got the better of a patient. The next generation of patients felt it was in the best interest of their personal safety, even if that meant undergoing forced treatment when they would certainly not want to be subjected to that. That was a position they shared increasingly with both the authorities and the public.

Zulbiye signifies a tipping point in views on mental illness and safety in The Netherlands that affected all the parties involved. And so did the patients view, caught between a rock and a hard place.