Executive summary

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Requests for advice

Some of the patients suffering from serious, chronic psychiatric problems have no contact with healthcare services. They are regularly in a state of acute need. In spite of this, they fail to receive any psychiatric care or even actively avoid it. What is the extent of the problem, what are the causes and how could changes in healthcare and legislation contribute to more effective care for these patients? This report focuses on these questions.

Extent of the problem

Every year, there are around 24,000 people with serious psychiatric problems who have no contact with healthcare services. These patients are not hospitalized and often do not apply for any other forms of help.

Within this group, an estimated 8,000 people are regularly in acute need of help (for example, when their condition deteriorates and they suffer serious delusions or hallucinations, sometimes in combination with addictive disorders). These patients often have major social problems, such as homelessness and an absence of food or money. They are unable to properly look after themselves and often have no contact with their families.

This group of around 8,000 people does not seek or receive the help that care providers, family members or involved others believe is necessary. They are sometimes a

burden on their environment. However, people can also become isolated and neglected, sometimes visibly on the street but often out of the view of others.

Causes

There is a considerable gulf between the supply of, and demand for, healthcare for this group of non-hospitalized patients. The present situation is the result of a range of complex factors, whereby three distinct clusters can be identified.

1 Greater and more complex need for healthcare provision

The demand for healthcare provision from this group of patients has become greater and more complex. Demand has risen as a result of vulnerable people becoming more easily sidelined in today's society. The traditional social safety nets of mutual help in local village communities or neighbourhoods have been replaced by widespread networks of people who keep in touch because they have something to offer each other. Anyone who has no 'added value' is excluded. This marginalization is also visible in the job and housing markets. The problems are greater in the big cities. Drug addiction is another factor that can contribute to marginalization and that can furthermore worsen a disorder. All of these developments have thus increased the need of this specific patient group for healthcare provision in recent decades.

The need for healthcare provision is complex because this group of patients often avoids contact with the health services. People often do not realize or recognize that they are ill and that they put themselves at risk if they do not receive help. However, they may also reject help following previous bad experiences, such as a traumatic compulsory admission. The situation becomes even more complex when people have a range of problems, such as a combination of a psychiatric disorder, addiction and health problems resulting from poor nutrition, smoking and the lack of standard medical healthcare from the general practitioner and dentist. Multiple problems are becoming increasingly frequent.

2 Lack of specific, appropriate help

Over the last thirty years, mental health care in the Netherlands has been moving towards taking long-term patients out of medical institutions. Instead, there arose a wide variety of small units, sheltered housing, day centres and ambulant care offering people with chronic psychiatric disorders a better quality of life. However, the group of non-hospitalized patients with serious psychiatric needs is unable to take advantage of these new forms of care. Moreover, the help provided does not always meet the specific needs

of this group (such as a combination of psychiatric care, practical assistance, housing, safety and food).

Combined help programmes are more difficult to provide because organizations in the public sector are forced to focus on their core business. It is their ‘raison d’être’, as it were. This situation affects the police force, parts of the healthcare service such as general practitioners and hospitals, as well as workplace, social services and housing authorities. These organizations are increasingly coming to recognize the problems of this patient group. However, the responsibility is easily shifted to mental health care.

Within the area of mental health care, certain factors also contribute to the gulf between the supply of, and demand for, care. Patients do not always feel that they have been well treated. There is sometimes insufficient expertise to deal with patients who are difficult to reach and families do not always receive satisfactory support. Mental health care and drug addiction services also lack a common approach to patients with multiple problems.

3 Lack of uniform legislation

Developments in legislation also play a role in the lack of alignment between psychiatric patients and healthcare. The Psychiatric Hospitals (Compulsory Admission) Act (Dutch acronym, BOPZ) and the Medical Treatment Contracts Act (Dutch acronym, WGBO) have considerably improved the legal position of psychiatric patients. Regulations regarding compulsory admissions have been tightened in comparison with the 1884 Lunacy Act. The patient must be deemed to be a ‘danger’ to himself or others and the patient must clearly indicate that he/she refuses to be hospitalized. Respect for the autonomy of the patient has thus become more crucial to the relationship between patient and carer.

The reverse, however, is neglect and the inaccessibility of essential care services to the patients who form the subject of this advisory report. Amendments to the BOPZ have since resulted in a legal framework for a number of new forms of help, including ambulant care, sometimes featuring strong persuasion rather than legal coercion. However, this has also increased the ambiguities. The interpretation of the term ‘danger’ can vary considerably in practice. This inevitably means that care providers sometimes fail to intervene when they might have done so, while in other cases more force is actually applied than is legally permitted. Moreover, not alle new forms of help that have been legislated for are relevant for the psychiatirc patients this report focuses on.

All these factors together (patients, healthcare provision and legislation) contribute to the gulf between the supply of, and demand for, care. It is difficult to point to direct

influences. For each patient, there can be a different combination of factors that results in the failure to receive the appropriate care for just this situation.

Possible solutions

The starting point in the search for solutions is that psychiatric patients do not benefit from ‘being left alone’ if they themselves do not seek help or even actively avoid it. Of course, their right of self determination must be respected in principle. However, where vulnerable people are concerned, protecting their rights can lead to neglect, isolation and degeneration, which in turn can threaten their right to care.

The right balance must be sought in every situation. Healthcare services and legislation must make that possible. In the future, more efforts should be made to ensure a continuum of care, allowing more scope for intervention in the area between freedom on the one hand and coercion on the other hand. Care providers will then feel less pressured into respecting either the right of self determination or the right of care.

Care providers will be able to search for a form of care that accommodates both needs as far as possible. The extent to which a patient is able to act in his or her own best interest will determine the extent of the influence of the care provider. What someone states to be their wish does not have to be taken at face value. There is room for dialogue and negotitiation. Even where strong persuasion or legal coercion are applied, these are aimed at enabling the patient to eventually better exercise the right of self determination.

Two developments are essential for more effective care, bearing in mind these starting points.

1 Intensification of coordinated care intervention

Patients who are difficult to reach and not able to use the existing facilities, or who have rejected help, must be actively approached. This so-called care intervention has already made some progress, but can also be further developed. Care providers will have to adjust their goals for this. Making and maintaining contact already constitutes a major success. Offering practical guidance is also important. It is only then that treatment can possibly be considered.

The range of facilities must also correspond better to what patients need. In other words, it must offer not just medical treatment but also practical help. More beds for patients with acute needs will have to be provided. Collaboration with other organizations is an important prerequisite for all of this. Care intervention teams can coordinate the essential combination of care. Patients will thus gain access to facilities that were hitherto inaccessible to them because they were either unaware of their existence or they were unable to find the right ‘counter’. In order to guarantee patients’ rights in this care

intervention, well qualified care providers must ensure that their patients are fully informed, and these care providers must act according to guidelines.

2 Include the continuum of interventions in legislation

Recent amendments to the Psychiatric Hospitals (Compulsory Admission) Act have already resulted in more opportunities for providing care to non-hospitalized patients with serious psychiatric problems. On the basis of a conditional judicial authorization, patients can now be given the choice between clinical compulsory admission and ambulant treatment. However, even then there must be some element of ‘danger’ involved. It is thus still not possible to offer help at an earlier stage.

In the long term, the Psychiatric Hospitals (Compulsory Admission) Act should be amended in its totality. It must then be considered whether we can retain the distinction between compulsory admission and compulsory treatment. After all, the actual and moral defence of compulsory admissions is that treatment is vital. Instead, a new law might be able to stipulate a continuum of possibilities for clinical and ambulant treatment that runs from intervention and persuasion through coercion to compulsion. A special committee could be installed to advise the Government on such a new law.