An open science paradigm shift for the wicked problem of mental healthcare

Keynote speech Jim van Os – 386th Dies Natalis of Utrecht University

Every developed country has a mental healthcare system, to which it allots around 10% of the total healthcare budget. These systems vary widely from one country to the next. Yet there is one point on which all countries agree: the mental healthcare system does not function as it should. In the Netherlands, too, one critical report after another has been published on the growing waiting lists, lack of access to care, increasingly common use of force and the exodus of professionals from the healthcare sector. In 2017, the United Nations even released a scathing report on the practice of modern psychiatric medicine.

It is clear that psychological suffering and the societal response to that suffering – mental healthcare – constitute a 'wicked problem' that demands an answer. This is an urgent issue, because psychological suffering in most cases emerges in adolescence and hence particularly affects young people. The pandemic, together with the unprecedented proximity of the war in Ukraine, has further increased the urgency of this issue, especially among this group.

But where will we find the answer?

A notable feature of the mental healthcare system is the self-reflexive nature of the thinking about it, which appears to be caught in an echo chamber. A small group of specialists and policymakers unquestioningly assume the validity of their knowledge and interests. They attempt to formalise solutions in so-called framework agreements for mental healthcare.

The danger of this kind of approach is that it doesn't bring to light how one's own blind spots are part of the problem. Open science is the movement that specifically seeks out those blind spots by examining problems in society not from an exclusive perspective, but rather through a multidisciplinary and participative approach.

Might it be possible to solve the wicked problem of mental healthcare by taking an open science approach? This is what we have been exploring for the past decade in a multidisciplinary group with wide-ranging expertise. The results are astounding. And, more importantly, they have prompted a paradigm shift and concrete, disruptive experiments in the mental healthcare sector.

I would like to tell you more about this.

We reached out to academics in the humanities. *Philosophers* had an immediate and salient response. Why, they asked, is the concept of psychological suffering so strongly associated with the brain? This isn't much help to patients. While it may be so that you need a brain to experience consciousness, the essence of psychological suffering is that it is contextual, in continuous interplay with the environment; that people must find a way to cope with it; that it must be assigned meaning; and that, as it becomes more powerful and pervasive, it gains a more 'external' quality, as when someone hears voices. Yet it

would seem that these core qualities of psychological suffering are precisely the aspects which the mental healthcare system has deleted from its vocabulary. Is there not another way to approach this?

Sociologists urgently drew our attention to an old controversy that has once again become quite relevant: to what extent is society itself the root of illness? The combination of the pandemic and, more recently, war in Europe has further underlined this. Young people, living in lonely and insecure conditions, are expected to shape their own destiny in a society where everyone must struggle along their own path to the top; surrounded by social media images of beauty and perfection, and all the while witnessing the inability or unwillingness of politicians to tackle major issues such as climate change. Should young people consequently be treated as patients in the increasingly individualistic wellness industry known as mental healthcare, or should we be helping them unite within a resilient and activism-based system, as a means of forcing change?

Economists provided an astonishing insight as well. Because, they said, if we know that 20% of the population will experience significant psychological symptoms in a given year, and we know the capacity of the mental healthcare system is 8%, doesn't it stand to reason that there will always be waiting lists? Demand will inevitably remain far greater than supply, unless there is also an additional form of non-regulated, easily accessible and (where necessary) anonymous *public mental healthcare* that everyone can turn to at any time. Online *eCommunities* can serve as the basis for a new public mental healthcare system. Examples of this are Proud2bme.nl and PsychosNet.nl, which are currently still informal meeting spots with a rudimentary budget which nevertheless attract millions of visitors each year. These virtual visitors come in search of information, chats, blogs, consultations, fora, a sense of connection and tools for self-management. Might these eCommunities not be the start of a new public mental healthcare system?

Meta-research is a relatively new discipline. This scientific field deals with the question of how useful and relevant the results of research actually are. Scientists conducting meta-research made two remarkable discoveries. The first was that people with the same mental health diagnosis differ as much from one another as they do from people with a different mental health diagnosis. In other words: the diagnoses are ineffective because each individual has more unique characteristics than commonalities with other people.

Secondly, they discovered that all treatments in the mental healthcare system have the same weak effect. It seems that every treatment is slightly effective for every disorder. The explanation for this is simple: the reason that people start feeling better during treatment has to do with the 'click' between patient, care provider and the type of treatment ritual. The exact technique of the treatment or the nature of the mediation *itself* is of lesser importance. The basis for evidence-based mental healthcare lies not in technique or molecular chemistry, but in relationships and rituals.

Anthropology further dissected the field. How can it be, anthropologists asked, that everywhere in the world, psychological suffering is associated with the spiritual realm, while the mental healthcare system reduces it to a 'disorder of the mind'? Patients are turning in droves to the shaman, the 'wounded healer' or the spiritual guide for special rituals, psychedelically expanded horizons, body-oriented ceremonies or animal-led training sessions. In other words, for things they cannot get from the mental

healthcare system. Is there not another way to approach this? Are these not relationship-based treatment rituals, too?

Social geographers provided an entirely new insight that had not yet occurred to anyone else. How is it, they asked, that consumers of mental healthcare – as opposed to care from GPs or medical specialists – show such a remarkably strong social gradient? If the mental healthcare covered by national healthcare insurance has such a strong correlation to social problems, should it not go hand-in-hand with the social care provided under that other law, the Social Support Act (WMO)? This is not what we see happening in practice. Is there not a better way?

What we do see, according to the *pharmacoepidemiologists*, is that in some areas, up to 12% of the adult population (mainly women) take antidepressants. Is it not the case, they wonder, that we are simply numbing the emotions of people bearing the brunt of social problems? Is that the purpose of the mental healthcare system?

We also heard from those in *Health Services Research* and the complexity sciences. If we look at the current mental healthcare system, they said, we see the classic problem of a linear system in which the treatment of patients is escalated through a series of increasingly drastic treatments based on strict referral criteria. Yet we know that this approach does not work on something as variable and complex as psychological suffering. It is much more effective to design a kind of ecosystem, a self-organising adaptive system in which patients can move freely from one component to another as they choose.

And finally, we learned from the knowledge gained by patients themselves. *Patient engagement* is the field of *experiential knowledge and expertise* gained by people who have lived with – and survived – psychological suffering. According to this experiential knowledge, psychological suffering can be seen as the start of a personal existential learning process that requires education to complete. This education can be found in what is known as a *recovery college*, where lessons are taught by experiential experts. Patients teach other patients how to literally reinvent oneself along the path to a meaningful existence – even in the face of permanent limitations. In the Netherlands, these recovery colleges are popping up everywhere you look, but always outside the official mental healthcare system. Couldn't greater cooperation be possible in this area? And ideally, in the form of true co-creation?

That more or less sums up the multidisciplinary, open science-based exploration of the wicked problem of mental healthcare. A wealth of insights and solutions were harvested in a relatively short period of time. But it goes further. Because in a number of regions in the Netherlands, and based on this open science exploration, people are working to accomplish the actual transformation into a mental health ecosystem. The first steps have already been taken. But what does the reality look like? What examples can I give you?

Lina is a 19-year-old refugee from Somalia with a traumatic past. She hears voices in her head, accusing her of terrible things. The voices tell her not to talk to anyone about them. She is having increasing difficulty keeping up in her nursing degree programme. A lecturer notices that Lina is struggling and suggests that she turn to the chat in the eCommunity of the mental health ecosystem. She can participate in this chat anonymously. There, at 11 in the evening, Lina chats anonymously with Suzan, a

Master's student in Psychology who works in the ecosystem. Suzan has experience with psychosis in her own family and recognises some of the signs. After chatting a few times, she gains Lina's trust and together they try to develop strategies to help Lina be less susceptible to the voices' influence. Suzan also tells Lina that a group for people who hear voices meets every Thursday at the local recovery college, led by an experiential expert, and that Lina can join the group without a referral. In the group, Lina meets other women with intense childhood experiences. One of the women has had positive experiences with a mental health therapy known as EMDR. The facilitator of the group asks a local psychologist – who is also a member of the ecosystem – if Lina can receive a number of individual EMDR sessions. The psychologist agrees and meets with Lina at the recovery college for a session on several occasions. However, after a few sessions, Lina feels that EMDR is a strange ritual and asks if she can talk to a Shaman instead. Another psychologist in the ecosystem has experience with shamanistic work in line with the four higher-order elements of evidence-based treatment. The spiritual rituals of this care provider help Lina and, although the voices have not stopped, she is better able to manage them and they trouble her less.

This was a brief example from real-world practice. For those familiar with the status quo, the contrast is quite obvious. And even if you are not familiar with the current system, you will hopefully recognise the elements of choice, easily accessible and anonymous public mental healthcare, making use of experiential knowledge and experiential expertise, a flexible and improvisational work method on the mental health specialist's part, no diagnostic medicalisation, co-creation and mutual support within the ecosystem and, potentially, identifying spiritual meaning – all within an evidence-based framework.

Taken together, this may well be enough to speak of a potential scientific gestalt switch à la Thomas Kuhn, which a discipline generally encounters once every 25 years.

And we are extremely pleased about this – it demonstrates that open science can help to tackle a wicked social problem. Rather than digging ever deeper within a closed system, this is about conducting a broad search, pursuing disruption and co-creation with the actual people involved.

Thank you for your attention.