

# The Complexity of Mental Healthcare and its Consequences for Doing Good



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# **The Complexity of Mental Healthcare and its Consequences for Doing Good**

De Complexiteit van Mentale Gezondheid(szorg)  
en De Consequenties voor het Oordeel Goede Zorg

(met een samenvatting in het Nederlands)

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# **PART I**

## **Chapter 1**

What is this thesis about?





## *Introduction*

This thesis attempts to develop ways to look at our system of mental healthcare beyond the status quo. It therefore perceives practices and structures that do conform to the 'psychiatric gaze' with which we have become accustomed to examine mental suffering. In order to remain agnostic in our approach and not succumb to the temptation to 'know' where in fact 'not-knowing' is the norm, we turn to complexity science to provide direction in rediscovering the world of mental suffering and what society's response to this should be.

From the perspective of complexity sciences, mental healthcare is not about individual elements but rather about how several factors in a system are interrelated and interconnected. From such a point of view, there are no clear boundaries between factors like mental healthcare professionals, the mental healthcare system, the mental healthcare providers, the mental healthcare clients and the mental healthcare context. Mental healthcare is a system, and as such influenced by other systems such as politics, the economy, the labour market, science, the client movement, fellow care providers in the healthcare chain and society. Given the fact that numerous actors are involved, mental healthcare is a *complex system*.

This thesis dwells on the complexity of the various interacting domains of this system such as: client experience and client needs; current attempts at linear science of mental problems and the ensuing focus on evidence-based, disorder-oriented, guideline-prescribed standardised practice; the goals of health insurers and governmental/European rules for more transparency with measurable results; institutional cultural characteristics such as religion; population characteristics particularly socioeconomic stratification and, finally, commercial forces attempting to find their way into the mental healthcare market. I also introduce the meta-level of how these topics reflect my *own* journey through the incredibly complex Dutch mental healthcare landscape over time. During the first years of my research, my endeavour was mainly about *why* we should start taking knowledge from complexity sciences seriously, in addition to the linear application of science in mental health. In the subsequent phase, there was more room to describe *how* complexity sciences could contribute. Finally, I found out *what* can be worked out as well. I still do not fully understand, but the application of complexity science has helped me make sense of it all. At the end of the day, when we understand the complexity of mental health and mental suffering, as well as society's organised response to this; and when we accept the consequences of this analysis for the judgement of good care, then *work* (after Hannah Arendt) and following procedures are not acceptable anymore. What is required then is to act: to speak out and start a discussion

on the topic. This is exactly what this PhD thesis is about: to share knowledge, to speak out and start a debate.

In order to address the above topics, the thesis is divided into four parts:

In **PART I**, the background of the research is outlined. **Chapter 2** outlines the context of the start this research in 2010 and the motivation for the research question: ***What is the complexity of mental healthcare and its consequences for doing good?*** That was the time of the heyday of the dictum: “to measure is to know”. In the twelve years that this study has been running, the conviction that “measuring equates knowing” has weakened, and space has become available to recognize and acknowledge the complexity of mental healthcare.

**Chapter 3** offers a glimpse into the world of an external PhD student who, in addition to her full-time job and against the currently established norms, is conducting research into a new field: complexity sciences. Throughout the years, her research has focused on the complexity of good care in the mental health sector. The perspective, approach and/or themes have evolved over the years. Therefore, my sub-research or publications relate to diverse fields or domains, such as primary care psychology, the Christian mental health service, healthcare fraud, mental health at the European level, preventing the outplacement of children from families with multiple and complex problems, the need for a new scientific paradigm within the mental health service and, finally, the complex relationship between healthcare costs and population characteristics.

In **PART II** the reader encounters the research that was carried out. **Chapter 4** provides an overview of the research findings and in so doing answers the research question. This was so chosen because complexity science, with its own terminology and concepts, remain unknown to many. By placing the answer of my research question at the beginning of my thesis, the expectation (or hope) is that a solid and especially coherent foundation can be laid with more understanding of the research method and the sub questions that this thesis addresses.

**Chapter 5** addresses the question *What are the theoretical foundations underlying the complexity of primary care psychology?* It discusses the ontology, epistemology, methodology and ethics of primary care psychology and describes the possible added value of complexity sciences.

**Chapter 6** deepens this research by analysing 113 vignettes in which primary care psychologists describe everyday situations which they experienced as complex. The research question here was: *What patterns can be analysed from vignettes describing*

*messy and confusing problems in the complex context of mental healthcare to obtain a better understanding of the complex dynamic reality of primary care psychology?* In this research project, the interconnectedness and interdependency of treating people with mental health problems, dealing with the family and/or employers, collaborating with other care providers, treating within the rules of the Mental Health Act, struggling with dilemmas and having mixed feelings, become apparent.

**Chapter 7** was a long-term study from the European Forum for Primary Care (EFPC), co-funded by the Norwegian European PRImary care Multi-prOfessional Researcher network (PRIMORE). This chapter highlights the need for a paradigm shift and describes the threats and opportunities related to mental health based on 14 themes. These themes were developed and discussed interactively during the EFPC conferences between 2012 and 2019.

**Chapter 8** explores whether the added complexity of incorporating existential values would fit within the current framework of providing mental healthcare. This is an exploratory study at the policy level, how (existential) values are on the one hand essential and on the other hand remain hardly mentioned in the policy of a biomedically oriented mental healthcare system. It describes the complexity of providing Christian mental healthcare and makes suggestions to look more broadly at recovery and the organisational model that is needed.

**Chapter 9** deals with the complexity of healthcare fraud and addresses the question *What is the right thing to do in case of presumed healthcare fraud and how to do this right?* It describes the roles of the fraudster and the whistle-blower and shows the complexity of not knowing what is “doing the right thing”. This study makes use of Hannah Arendt’s distinction between labour, work and action. An explicit call is made for less work and more action.

**Chapter 10** describes research into the complexity of counselling and treating families with multiple and complex problems. It addresses, in a mixed-method research project, three sub-question: *First, What are the experiences of caregivers in dealing with families with multiple and complex problems and the ensuing family-focused interventions?*

*Second, What problems do families with multiple and complex problems struggle with the most, and are these inter-related? To what degree are these problems related to the (imminent) out-of-home placement of children?*

*Third, What potential means of improvement become apparent as a result of the research findings?* It shows how an unequivocal policy of ‘more family-oriented interventions’ to

prevent out-of-home placement can result in a rather chaotic situation with limited effectiveness. It suggests tools for how things can be done differently, for instance by deploying a client supporter and/or peer support that enhances the family's self-direction.

**Chapter 11** is an essay which, like chapters 5 and 7, focuses on initiating a dialogue to discuss a paradigm shift within science, from the perspective of complexity science. It describes the gestalt switch that is taking place within the mental healthcare sector as a result of the decompartmentalization of care and support and the growing collaboration between the two. This is in contrast to science and its associated funding, which as yet is failing to adequately reflect this development.

**Chapter 12** is also about an insufficient match, this time between the supply of mental health services and the population profile. It shows that in urban areas and areas with a higher density of mental health services, mental health activity is more intensive and disconnected from the population profile. It also explores whether the social determinants of mental healthcare are being addressed sufficiently in the Integrated Care Agreement 2022.

**Chapter 13** describes the patient journey of three persons with serious mental problems. These are three poignant stories that show that good care is above all about the experience of being heard, seen and understood and that recovery is interdependent and interconnected with patients' everyday lives.

**PART III** discusses the meaning of this research and proposes follow-up research.

**Chapter 14** combines the various research findings by articulating them as propositions. These propositions are substantiated and explained in relation to the previous chapters. Some propositions are accompanied by general suggestions for follow-up research.

**Chapter 15** describes a suggestion for follow-up research in more detail.

In **PART IV**, the concluding section, **Chapter 16** offers an English-language summary of this research and **Chapter 17** the Dutch-language summary.

**Chapter 18** offers an overview of all publications. In addition to the publications included in this thesis, I co-authored a number of other scientific publications and wrote a number of opinion pieces.

**Chapter 19** provides an overview of all the presentations and a master class I gave at international conferences in America, Belgium, France, Greece, Italy, Latvia, the Netherlands, Norway, Portugal, Sweden and Turkey.

In **chapter 20**, I thank everyone who contributed to the realisation of this thesis.



# Chapter 2

Context





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## Context

In 2010, when I started this research into the complexity of good mental healthcare, it was the heyday of “Stepped Care” and “Cognitive Behavioural Therapy”, and the time when disorder-oriented care standards were introduced (1). The year 2010 was also a turning point for the already introduced philosophy of market-based Routine Outcome Monitoring (2). The Trimbos Institute, a Dutch Association of Mental Health and Addiction Care, and Zorgverzekeraars Nederland, the umbrella organization of ten health insurers in the Netherlands, reached an agreement concerning the submission of Routine Outcome Monitoring data to the Foundation (3). With the obligation to carry out Routine Outcome Measurements (ROM) came the need to express treatment results in measurable and quantitative terms. It opened the door to clients for whom a “measurable result” could be achieved. Unfortunately, it put the group of clients with complex problems in a difficult position, as their treatment results were arduous to measure. How do you measure relapse prevention and/or improvement of quality of life? ROM nevertheless was thought to contribute incrementally to competition for the best treatment outcomes in the mental healthcare sector. It was an essentially linear vision of measurable cause and effect as applied to the area of mental health. At the time, the linear biomedical approach that was introduced with the advent of DSM3 in the 1980's still dominated the field, although already there were voices of dissent.

The linear cause-effect ROM as applied to mental healthcare troubled me greatly. Not only because of the (then still) likely end of primary care psychology with its biopsychosocial vision and contextual approach, but also from the perspective that the more you think and act in compartments, the more likely it is that people will be excluded for failing to meet the criteria of compartment A, B or C. From my perspective, what was needed instead was research into how factors are interrelated. How do they influence each other, how can we learn to understand the dynamics and then influence them for the better?

My research thus began against the grain with ***What is the complexity of good care in primary care psychology?*** When primary care psychology (indeed) disappeared, the research was broadened to good care in mental healthcare in general. ***What is the complexity of mental healthcare and its consequences for doing good?***

After a few years, the tide began to turn somewhat, and recognition of the complexity of mental healthcare has since increased. The medicalisation of mental symptoms has been called into question more and more (4). Viewing mental health solely in linear terms of disorders, malfunctioning brains, evidence-based guidelines and disorder-oriented care

pathways with competitive routine outcome monitoring, lost evermore support (5–7). There is a growing awareness that the application of classical scientific knowledge within the mental health services is fraught with problems (8–12).

The United Nations was outspoken in its call for psychiatrists ‘to act with courage to reform a crisis–ridden system built on outdated beliefs’ (13). The Netherlands Scientific Council for Government Policy indicated that the healthcare system has become (too) complex, making it increasingly difficult for citizens to find their way (14). For instance, there is a rigid distinction in mental healthcare for young people under and over 18 years old which in practice leads to many problems (15–17). The Ministry of Health indicates in its discussion paper *Zorg voor de Toekomst* [Care for the Future] that the way care is organised is extremely complex (18). The Health Care and Youth Inspectorate indicates that tackling waiting times in healthcare is an increasingly complex issue (19). Healthcare managers also feel trapped between result–oriented, directive care and complex daily practice (20). Psychiatrist Damiaan Denys describes in his book *Het tekort van het teveel, de paradox van mentale zorg* [The deficit of the excess, the paradox of mental care] the paradox of mental healthcare with its contradictions and fallacies (21). The recognition that there are complex issues that cannot be solved within the regular framework has led to the development of Network Psychiatry, in which collaboration takes place across domains on the basis of complementarity, following the needs of people with mental health problems (22).

Floortje Scheepers, psychiatrist and director of Science at Phrenos Research Centre and professor of Innovation at the faculty of Medicine, UMC Utrecht, emphasises that human behaviour is too complex, dynamic and changeable to be contained within linear processes (23). Jet Bussemaker, Professor of Policy, Science and Societal Impact and chair of the Council of Public Health & Society, ‘argues for a creative, flexible government with a heart, which does not stare blindly at bureaucratic numbers, but offers its citizens something to hold on to in complex times’ (24). In July 2021, Paul Blokhuis, State Secretary for Health, Welfare and Sport, admits “There is a perverse incentive in this that leads to cherry–picking, irreverently put” (25), meaning that mental health institutions are avoiding people with the most serious problems in favour of patients with lighter problems and that this is a consequence of the funding system.

Jim Van Os and Myrre Van Spronsen made a case for a new psychiatry of collaboration, saying “God we are not” (26). This new psychiatry, developed together with Philippe Delespaul, is called GEM, which stands for Ecosystem Mental Health. It is a network that tries to bring together all the competencies and perspectives for action needed to facilitate change, perspective and participation, across the different contexts of mental suffering, in a living and learning system of collaboration, based on a strong shared

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vision of values-based work (27). GEM is all about interconnectedness, interdependencies, dealing with uncertainty in good trust with the client as a central player. It seems we are finally moving towards the direction of Harry Kunneman's *amor complexitatis*, towards acknowledging and embracing the complexity of ourselves, of others, and the world (28).

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## Chapter 3

The complexities of an external  
PhD project about complexity





## *Interconnectedness, interdependency and uncertainty*

As described in the general introduction, complex systems are mainly about the interconnectedness and interdependencies between systems and about the discretionary space for organizations and professionals to deal with uncertainty and unexpected feedback loops. No matter how purposefully and methodically one works, there will always be unexpected twists and turns that will call on your self-organizing and adaptive capacity. It stimulates one's adaptive capacity and shows perspectives one could not have imagined before. This is also what happened during my research process on the complexity of mental healthcare. The plan was to investigate the complexity of primary care psychology and, after various detours within the mental health sector, ended up with research into a Mental Health Ecosystem. In this chapter, I will outline this process in its context.

## *Three principles to hold on to*

As a philosopher of science, it is customary, on the one hand, to investigate with an open mind and, on the other, to provide a structure for your thinking. In my development as a scientific researcher, I have adhered to three principles. These are the dialogical principle, the principle of organizational recursion and the holographic principle of Edgar Morin (1). First, is the dialogical principle. The dialogical principle seeks the connection between the various perspectives in order to create a shared perspective or multicolored reality. In the mental health sector, I saw many 'realities' that were difficult to unite. Sometimes it seems easier to make a preferred perspective dominant and make other perspectives less important. My pitfall was to turn my back on classical science methods and to be enthusiastic about complexity sciences. The dialogical principle has helped me to view multiple perspectives from multiple angles, precisely at those moments when my emotions were running high. The pleasure of experiencing multiple perspectives simultaneously and equally gave me great satisfaction. The second principle is the principle of organizational recursion where the producer and the product are the same. Healthcare professionals are shaped by (dominant) norms and values in healthcare and produce (dominant) norms and values in healthcare themselves. This principle has challenged me to keep looking critically at my own role as a researcher. How do I move within the mental healthcare sector and the world of scientific research, and which research literature do I read and use? The concept of normative professionalism by Harry Kunnenman has been helpful in this process (2). Everything you do has a normative charge and, above all, a moral responsibility. This is also in line with my graduation subject, ethics. The hologrammatic or holographic principle indicates that

'the part is in the whole as the whole is in its parts.' You cannot understand the parts if you have no knowledge of the whole and vice versa. This has stimulated my interest in the dynamics between part and whole. It helped me when there were discussions about the two sides to look at the dynamics in this discussion rather than learning to understand both extremes.

### *Interconnectedness and interdependencies in the context of my research*

As an external PhD researcher with a fulltime job, this research has not been conducted in a scientific bubble but has been moving along with developments in daily practice and my professional life. From a linear perspective, it can be seen as a research project that goes in "all directions". From a nonlinear perspective, this research was carried out in an adaptive way in which no topic, related to the complexity of mental health that crossed my path, was shunned. A chronology of the context of the research and publications follows, along with an explanation of how the specific research question is related to the central research question.

### *From start to first publication*

In 2008, I first came into contact with complexity sciences through my work at the University for Humanistic Studies. Drivers of the complexity sciences at the time were Prof. Harry Kunneman and Dr. Kees Pieters, in collaboration with Paul Cilliers at the Stellenbosch University of South Africa. Complexity sciences appealed to me because I saw a potential bridge here between the sometimes unpredictable dynamics in practice and the need to understand those dynamics scientifically. One of the first authors I delved into was Edgar Morin, a French sociologist and philosopher. His book *On Complexity* provided me with a solid foundation on which my understanding and knowledge could grow (1). The statement below articulates what I was looking for and why, over the years, I read almost everything Morin has ever written.

*We need a kind of thinking that reconnects that which is disjointed and compartmentalised, that respects diversity as it recognises unity, and that tries to discern interdependencies. We need a radical thinking (which gets to the root of problems), a multidimensional thinking, and an organisational or systemic thinking. (1)*

In 2010, at the start of my PhD research, I worked at the National Association of Primary Care Psychologists as a policy officer and researcher. Promotion of expertise and

profiling of primary care psychology were two prominent areas of attention. Within the mental healthcare sector, there were many discussions about how 'scientific' the primary care psychologists were, as well as about the question, "what is good care?" At the time, working (only) according to disorder-specific guidelines equalled good care. Although primary care psychologists worked based on the advice of these guidelines, they tailored them for each client and their context. This was, however, not seen as a "scientific approach". The counterargument of the primary care psychologists was that their patients had more problems than just a mental illness. Treating only the disorder underestimated the complexity of their life circumstances. With a background as a philosopher of science and a graduate in ethics, I got interested in the complexity of good primary care psychology.

Primary care psychologists struggled a great deal with their position in 2010 (3, 4). Psychologists had received additional training (expertise enhancement) and treated mental problems based on the biopsychosocial and psychodynamic model and from a contextual perspective (5, 6). They had been working alongside family physicians for decades and provided annual data to the Netherlands Institute for Health Services Research, NIVEL (7–9).

Traditional specialised mental healthcare in those days had to move away from the hospital setting and into the neighbourhood environment, where the primary care psychologist had their small practices. The introduction of the practice support physician-mental health (poh-ggz) in primary care also became a reality (7). There was little collaboration; on the contrary, competition became more intense (10). Specialised mental healthcare did not (want to) make use of the models already developed by primary care psychologists, and developed their own models, such as the KOP model and brief psychological interventions (11). The methodology of primary care psychology, which was developed based on self-organization (6), was robust but received little status in the discourse of the time. Therefore, the need for a scientific foundation to demonstrate how good care could be provided by primary care psychologists was more than welcome.

In the early years of my research on the complexity of good care, the main focus was on creating space for other perspectives beyond the classical view of science within psychology. Framed in terms derived from the philosophy of Thomas Kuhn, my initial scholarly presentations were primarily aimed at making anomalies within the current paradigm negotiable (12). I hoped for a paradigm shift with more room for complexity. From this initial situation, I went to the 4th International Nonlinear Science Conference at the University of Palermo (Italy) in March 2010, and gave a plenary and poster presentation on the relationship between the demands of the client, the current demands of science with its evidence-based disorder-oriented guidelines and the goals of

health insurers and governmental rules for more transparency with measurable results. I made a plea for embracing complexity (rather than reducing it) in order to come up with a better estimation of the measurability of demand-driven primary care. During this conference, I was captivated by the world of dynamical systems theory, self-organization, neural networks, fractals, cellular automata, agent-based modelling and related forms of chaos, catastrophe, ramification, nonlinear dynamics and complexity theories within psychology and the social sciences. I became a member of the Society for Chaostheory (13). As a philosopher of science with many roots in daily practice, it was not easy to autodidactically understand and translate this information into my research on good care within the mental healthcare system in the Netherlands. The course, *Complexity and Evolution*, run by Prof. Dr. Francis Heylighen of the Free University of Brussels was very helpful in this respect (14). After an extensive literature review of various researchers in the field of complexity science and complex adaptive systems theory (15), I gave three presentations at scientific conferences in 2011. The first was at the International Congress on Qualitative Inquiry at the University of Illinois USA, where I discussed the complexity of normative judgments made by primary care psychologists. During this congress, I attended several mixed methods research master classes taught by Jennifer Greene (16). The second and third presentations were at the 21st annual international conference of the *Society for Chaos Theory in Psychology & Life Sciences* at Chapman University in Orange County, California USA. One presentation was about the tension between the simplicity of a linearly organized healthcare organization and the dynamics of daily practice. The other presentation was about the added value of Morin's principles of distinction and conjunction for the daily practice of primary care psychologists in making normative choices about good care. During the 21st annual international conference of the society for chaos theory in psychology & life sciences in Orange County, I was able to learn more about Big Data in individual cases. One case study in particular impressed me greatly. It was about a young woman with serious mental problems who was barely able to communicate. By combining all physical information (blood pressure, heart rate, muscle tension) with her non-verbal communication (recorded on camera and analysed using advanced software) patterns could be recognized. The patterns were compared with the daily routine in the clinic and so it became possible to determine which factors played a role in the quality of care and/or quality of life for this patient.

This context led in 2015 to the article *The complexity of primary care psychology: theoretical foundations*. The research question was *What are the theoretic foundations underlying the complexity of primary care psychology?* It was written to build a (first) bridge to a new scientific paradigm other than the dominant paradigm with its reductionism and determinism. It was published in *Nonlinear dynamics, psychology, and life sciences*, the scientific journal of the society for chaos theory in psychology & life sciences.

## *On complexity experienced in daily practice*

In 2011, in the run-up to the mental healthcare system changes from primary and secondary care to basic mental healthcare and specialised mental healthcare, there were many frictions. The then Minister of Health, Welfare and Sport, Schippers, wanted to cut millions from the mental health services by four interventions; introducing personal contribution for primary care, reducing the number of insured sessions from eight to five, removing those patients suffering from adjustment disorder from the insured package and by promoting more e-health. These cuts were wrapped in the double message of both collaboration and competition (17). I wrote an opinion article about this in the magazine *GZ-psycholoog* (10).

To strengthen the position of the primary care psychologist, Radboud University developed a program to become a certified primary care psychologist. This could be followed after completing the two-year post-master course to become a mental healthcare psychologist. To strengthen the scientific foundation of experienced primary care psychologists, an eight-day course entitled *The Science of Primary Care Psychology* was developed. This course was developed and organized by me as a researcher at the National Association of Primary Care Psychologists (LVE) and offered to the members of the LVE. Twenty-nine experienced primary care psychologists participated. The course dealt with the scientific basis and the social context of primary care psychology, the normative professionalisation of primary care psychologists, the complexity of primary care psychologists and various research areas related to primary care psychology. During one lecture on *The Primary care psychologist as a normative professional*, led by Prof. Dr Harry Kunneman, attention was paid to the skills needed to take a normative position professionally within the sometimes contradictory interests of the primary care psychologist (between legislation and regulations, professional code, social issues, expectations of the client, norms and values and personal vision of life). In the workshop, during this meeting, subgroups discussed illustrative cases that reflected the complexity of good care for primary care psychologists. The homework assignment was for each participant to write out three to five such cases according to a set format. A total of 113 vignettes were written. The research question was: *What patterns can be analysed from vignettes describing messy and confusing problems in the complex context of mental healthcare?* The research results were published in *Europe's Journal of Psychology, Vignette Research on Messy and Confusing Problems in Primary Mental Healthcare* (18).

## *The complexity of mental health at the European level*

In the year 2012, I was aiming for more connection with international developments in mental health in primary care and joined the European Forum for Primary Care. The first conference I attended was in 2012, in Gothenburg, with the title: *The Future of Primary Healthcare in Europe*. The congress was well organized, and there were meaningful discussions, but a vision of the future of *mental health* in primary care was missing.

At this conference, I gave a poster presentation on ethical monism and/or ethical pluralism that discussed the complexities of a supposed ethical monism. In this presentation, I engaged my interlocutors in a dialogue about how they determined good care and what influence the various sources (science, vision, employer, healthcare system, etc.) had on their judgment of good care. It was striking that the majority of the participants had strong opinions about what constituted good care for them, but in practice they followed the requirements of the healthcare financiers. In the few workshops and poster presentations on mental health during this congress, I met a limited group of colleagues each time. They were Jan de Lepeleire, Professor of General Practice KU University Leuven and coordinator of the medical department of University Psychiatric Hospital KU Leuven, Lisa Hill, RMN, MSc, MA EdD, researcher and completing her Doctorate of Education at Staffordshire University, and Ian Walton, MBBS, MSc, General Practitioner, Educator in Primary Care Mental Health. Collectively we felt that there needed to be a greater focus on mental health in primary care. This need for more attention to mental health in primary care was translated into action at this very conference. At the end of the conference, we were established at the general assembly as the EFPC mental health working group. Since then, this working group has provided (at least) one workshop during the annual conference on mental health in primary care. The themes of the workshops tie in with the annual theme of the EFPC and are also intended to discuss bottlenecks and solutions together with the participants and to share good practices. The bottlenecks raised by each country over the years could vary greatly. However, the themes of interest were fairly universal. After eight years of collaborative research, this led to the *EFPC Mental Health Position Paper 2020* (19) and an article on the scientific underpinnings of the themes in the statement in *Primary Healthcare Research & Development* (20). The themes of the EFPC position paper Mental Health are: access, co-creation, complexity in primary care, diagnosis of mental health disorders, education, inequality, information technology, leadership, model of care, prevention, research, self-care, spirituality and workforce development. The next step for the EFPC mental health working group is to create an overview of good practices, to share knowledge more easily and to keep the attention on these themes high. The working group collaborates where possible with other organizations such as The European Community based Mental Health Service

Providers (EUCOMS) Network and there are other links to relevant organisations such as Mental Health Europe (MHE).

From 2018, the EFPC mental health working group participated in the PRIMORE project of the European Primary care Multiprofessional Researcher Network (A European Primary Care Multi-Professional Researcher Network (21). PRIMORE is a research project of the Western Norway University with the aim of strengthening the synergy between health and primary care and the internationalisation of Norwegian research in this field. PRIMORE aims to improve the responsiveness and efficiency of health systems through community-based primary care. From PRIMORE, I contributed to the Masterclass: Interprofessional Primary Care Research, together with colleagues from Belgium, Turkey and Norway. As a follow-up to this masterclass, I guided a group of young researchers from Germany, Thailand, Kazakhstan and Turkey in a collaborative and interprofessional research project. Together they wrote a research proposal: Interprofessional Research during Covid times. This was presented at the annual (online) congress of the EFPC 2021 and at the closing conference June 2022 in Bergen, Norway.

### *From primary to secondary mental healthcare*

In 2013, the National Association of Primary Care Psychologists decided to strengthen their position by merging with the Dutch Association of Independent Psychologists. Together, they could represent the entire mental healthcare chain and share knowledge, strive to maintain the autonomy of the independent professionals, stand stronger against financiers, health insurers, the government and sector parties and operate more efficiently (22). This also meant that research into and scientific underpinning of primary care psychology quietly disappeared (4). I decided to leave the National Association of Primary Care Psychologists (prematurely). My interest in primary care psychology with its professionally complex challenges remained, but my drive to focus my research entirely on primary care psychology disappeared. This development had consequences for my primary research question *what is the complexity of good primary psychological care?* The essence remained, but the research question was broadened into: ***What is the complexity of mental healthcare and its consequences for doing good?*** Ironically, my field of work shifted towards specialized mental healthcare where I carried out two assignments as a freelancer. The first assignment was originally to implement a care program model that had been developed by the care advisory agency P5COM. This was a “traffic light model” according to which therapists could see in the colours green, orange and red to what extent the treatment was affordable. This model, which only allowed limited content control, generated a lot of resistance. After informative meetings with all teams and several key persons in the organisation, I concluded that I did not consider this model



morally justified. The model focused too much on money, and too little on content and went against professional norms and values. It was more money-driven than client-driven. There was also a lot of resistance at the national level to this model developed by P5COM (23). With the support of the employees, I received a modified assignment to develop new care programs (demanded by the health insurer) with sufficient autonomy for the therapists (demanded by the care professionals) and with enough room for customized care where necessary (demanded by the client council). It was successfully set up in a form of co-creation involving the healthcare professionals, the financial administration, the ICT team, the policymakers and the client council.

At that time, a national Administrative Agreement GGZ 2013–2014 came about. The Administrative Agreement was signed by 10 major parties, including the Minister of Health, the employers' association of healthcare providers, the umbrella organisation of patient organisations and various professional organisations. In this agreement, there was (still) a lot of confidence in the implementation of transparent care demand scores and the associated tariffs, confidence in being able to analyse differences between providers using ROM and confidence in being able to monitor referral behaviour, relapse and shifts in costs (24).

*The parties emphasise the importance of transparency of performance. To this end, they agree on a single language for quality and comparability of outcomes. Routine Outcome Monitoring (ROM) is part of this. Healthcare providers at all levels (with the exception of the GP function in mental healthcare) undertake to provide insight into the efficiency, effectiveness, safety and patient experience of the care they provide. Patient appreciation and experience will be structurally measured by means of ROM (24).*

This Routine Outcome Monitoring application through Stichting Benchmark GGZ managed to provoke a lot of discussion in the professional field (25–28) and led to a negative connotation being attached to the GGZ Benchmark Foundation. To avoid this, the Benchmark Foundation was disbanded. Akwa GGZ took over all data in early 2019. In turn, Akwa GGZ received a reprimand from the Authority for Personal Data because Akwa processed personal data on health for which it had no consent (29). Later that year, Akwa was ordered to permanently destroy the data, by order of the Authority for Personal Data.

The second assignment which I carried out was to develop a vision of good care in which Christian values were included. I did a literature search on the difference between the various models in which the vision of care was shaped, which ones included existential issues and which did not, and which would fit within the vision of Christian mental

healthcare. We had conversations about whether you could talk to a client about God and the Bible within mental health treatment, just as you sometimes talk to a client about the weather. We discussed how do you know, as a therapist, when faith is a support or a straitjacket that weighs one down. The extent to which a vision of care can be implemented also made clear the demands this puts on the organisational structure and the learning ability of both the organisation and the employees. This resulted in the article *De complexiteit van het bieden van christelijke geestelijke gezondheidszorg* (The complexity of providing Christian mental healthcare) in *Psyche & Geloof* (30). This article focused on the question *What is needed to incorporate existential values into the provision of mental health services?* Important elements are the existence of an information network throughout the organisation to stimulate the adaptive capacity of staff and to work towards a learning organisation. Working from a secondary mental healthcare setting and a healthcare institution with a Christian signature broadened my frame of mind and gave me new input on the various dimensions of good care.

### *Unexpectedly, a lot of uncertainty and healthcare fraud*

2019 was a blank year for me in terms of research. I was unable to do any research activity, nor attend or present at any conference, due to the complexity of my day job completely consuming my time and attention. Working at a mental healthcare facility that treated both youth and adults, I suspected (along with colleagues) the reality that up-coding (the practice of claiming more money from the health insurance company than was spent on treatment for self-enrichment) had been going on. This led to a year of frequent deliberations to ensure accurate reporting, and meetings with the bank, the accountant, the health insurance company, the Dutch Healthcare Authority and my lawyer. It was a year when there was increasing attention being paid to the problem of healthcare fraudsters, called “healthcare cowboys” (31). But unfortunately, information and advice for (potential) whistle blowers were virtually non-existent. In terms of Snowden’s Cynefin Framework, I found myself in a chaotic situation where cause and effect were no longer distinguishable and the need for stability was great (32). It was—quite unlike anything I could have ever imagined—a real-life study of good care and/or doing good. The stability I sought, and found, after my resignation and later the bankruptcy of the organization, was the scientific investigation of the complexity of healthcare fraud. This led in 2020 to a publication *The complexity of healthcare fraud—ethical and practical considerations* (33).

### *The complexity of good care when cocreation is missing*

At the beginning of 2020, on behalf of the Dutch Regional Service Team IJsselland (youth care), I was asked to start a study into the characteristics of families with multiple and complex problems and the experiences of youth care professionals with family-oriented interventions to support these families. The youth region had focused on more family-centred interventions and found broad support for this among both youth care and youth mental health services. Despite extra attention to prevent out-of-home placement of children, the number of children ultimately placed out of home remained on the rise. The underlying aim of this research was therefore to provide input for the ambulantisisation of youth care and advice on how to prevent out-of-home placements as much as possible. It was mixed-method research with interviews with 16 youth care professionals and an analysis of 206 cases of families with multiple and complex problems. It contained three research questions. 1. What experiences with Families with Multiple and Complex Problems do caregivers have with these families and with family-focused interventions? 2. What problems do Families with Multiple and Complex Problems struggle with the most and is there a significant correlation between the different problems? Are these problems related to the (imminent) out-of-home placement of children? 3. What potential means of improvements become apparent as a result of the research findings? The results were published in 2022 in the *Canadian Journal of Family and Youth* (34).

One of the most surprising results was that with every problem in the family added, there was a 10% increase in the likelihood that a child would be placed out of home. This also became relevant for the children of the families involved in the so-called *benefits affair*. Due to an excessively strict approach by the Dutch tax authorities, almost 50,000 families ran into serious financial problems (35). Families had to repay alleged tax fraud without any government support, causing many to lose their homes and experience severe mental health problems. The financial problems of the families due to the benefits affair in turn frequently contributed to an accumulation of problems within the family so that a child could no longer grow up there safely (36). A total of 1675 children of families involved in this affair were placed out of home at some point during the years 2015 through 2021. A total of 555 children were (still) in home placement by December 30, 2021 (37, 38). To solve the problem of the unsafe situation of these children, the choice was made to place these children out-of-home, instead of giving these families support to reduce the number of problems so the children could stay with their family. Families and stakeholders are now facing a new problem: how can the bond between the parents and the siblings be recovered? I was pleased to

hear that the Dutch Regional Service Team IJsselmeer took the results of this research seriously and changed their policy.

### *A paradigm shift (finally) in sight?*

Since 2020, as director of a self-direction and recovery centre for people with mental health problems, I have focused—in addition to my regular activities—on the complexity of integral collaboration with special attention to the issue of diversity within it. A self-direction and recovery centre supports residents with psychosocial problems to connect their personal needs to an extended offer of recovery. In everyday practice, this is not always easy... Seeking help in the Netherlands should be straightforward. The family doctor is easily accessible and free of charge. In every neighbourhood or village, there is a social team or community team to whom all possible questions can be directed, including complex care questions. There are quite a few client advocacy organizations that can advise and assist clients. The day-to-day reality, however, is more complicated. The workload of the family doctor and the community health workers is high and waiting lists for mental health services are long. Time to explore the personal background and the interconnectedness and interdependencies of all factors is limited. It is likely that there is a limited match between the personal worldview of clients and the bureaucracy of the healthcare system. In addition, there are high expectations for what people can organise and/or can initiate independently (39).

In the last ten years, there has been considerable further specialisation in the mental health care system. This has had its effect in terms of increasing fragmentation. For mental problems, one can go to a psychologist or psychiatrist who practices in the mental health sector, where there are teams specialised in certain disorders. For financial problems, one can go to a financial coach or debt assistance. If someone is lonely, he or she can join one of many community activities. If you feel unsafe in the neighbourhood, you can contact the community police officer or the community team. But what if you have psychological symptoms partly due to your overwhelming feelings of insecurity, you have lost your job and meanwhile your income has decreased considerably? Whom do you turn to then? Such questions are easily called complex. Not because they are intrinsically complex by definition, but because they are complex to solve because they fall under different laws and regulations and are carried out by different organizations (40, 41). In other words, these issues are cross-domain and it is precisely these trans-domain problems that affect recovery (42). The report *Blijvende Zorg* [Enduring Care] by the National Ombudsman pointed to the lack of equal co-creation and direction and the desperation of citizens to find their way but also recognised the persistence of this problem (40). Collaboration initiatives often run aground when they meet the institutionalised interests of procurers

and care providers (41). The Public Health & Society Council notes that trans-domain equal co-creation is required (41). Cross-domain co-creation should be connected to a variety of institutional interests within and between the different care domains. One of these co-creation initiatives is the mental health ecosystem (GEM). GEM is a network that wants to bring together all the competencies and perspectives for action needed to facilitate change (43). The emphasis is on the client's perspective and their participation in society. It is intended to be a living and learning system of co-creation. But how can we overcome the variety of institutional interests within and between the different care domains? How can we consolidate the gestalt switch that is now going on within the mental healthcare system? What consequences will co-creation have on how mental healthcare is paid for? Is now the time right to seriously talk about a paradigm shift? These questions and the possibilities of complexity sciences prompted me to concretize my collaboration with Jim van Os, who's work I had followed for years. The first article we wrote together was about the need for a paradigm shift that fits the ongoing transformation in mental healthcare. Complexity sciences offer opportunities to investigate and describe current developments within the mental health system. But it requires a gestalt switch in thinking and an openness to new concepts. After years of feeling like a voice in the wilderness, it now feels like the research I've done has landed in GEM. During the first years of my research, my plea was mainly about *why* we should start taking knowledge from complexity sciences seriously in addition to the classical method of science. In the subsequent phase, there was more room to describe *how* complexity sciences could contribute. At GEM, the *what* can be worked out as well.

The concept of an Ecosystem Mental Health is currently enjoying wide support. A relatively small group is active in regional pilots, and a relatively large group is interested in and follows the activities and reports. In addition, there are similar developments around the country that are not (yet) linked to the Ecosystem Mental Health framework but are using similar interventions and pursuing co-creation. I became involved in the development of integrated care for residents of Zeist with severe mental problems (EPA). Strengthening the social base, normalizing, and focusing on positive health formed the guiding principles. By providing more accessible support around the person, in which self-direction is not only given shape on paper, the expectation is that the quality of recovery will be increased and the costs will drop. In Zeist, there is also a great deal of support and shared values, yet this does not always seem to be enough. Change processes, not only in daily thinking and acting but also with regard to the necessary preconditions—such as finances and position as a discussion partner—require attention, time, patience and professionals who dare to take action.

It became time to look at how we distribute the available financial resources among all the stakeholders involved in mental healthcare. It has long been suspected that

the supply of care does not sufficiently match the care that certain groups with mental problems need. The group of people with problems in several domains of life, including severe mental problems, are on waiting lists for long periods (44) and specialized clinics are being closed down for financial reasons (45). By analysing Vektis data (database costs incurred under the Health Insurance Act) and socioeconomic data (from Statistics Netherlands) at the four-digit postal code level, it was possible to provide insight into the relation between the necessary care based on population characteristics and the care offered. In urban areas and areas with a higher density of mental health services, mental health activity is more intensive and dissociated from the population profile. This suggests a supply-driven overtreatment. The results were combined with the goals of the Integraal Zorgakkoord 2022 and published in *Vaktijdschrift GGZ* with the title: *Het moet beter, het kan beter, maar gaan we het ook beter doen?* (46) The suggested overtreatment by (some) local mental health services contrasts sharply with organizations within the domain of social care, such as the self-direction and recovery centres and the recovery academies, which have no structural funding. They are dependent on the goodwill of the local municipality. There is concern that this will put the envisaged equal co-creation within the Ecosystem Mental Health under pressure. This was partly the reason to do research into the views of political parties to finance these self-management centres and recovery academies on a structural basis. This research is in progress and is being done within the Program *Herstel Dichtbij* of MIND and the Oranje Fonds (47).

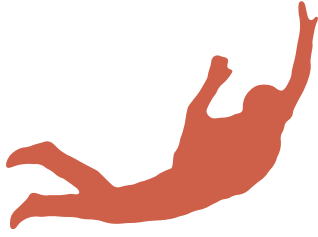
## *Conclusion*

The path I followed as a PhD researcher was not only about complexity but was also complex in itself (holographic principle). My research into the complexity of good mental healthcare was planned and organized. How the research went and what issues I would encounter, and the choices I had to make, were interconnected and interdependent with the issues I encountered and the developments within the mental health sector and society itself. For me, this interconnectedness, interdependence and uncertainty was scary at times, but also part of 'normal life' and a challenge to my ability to adapt. I have adapted to all this in a self-organised way and learned things that no one could ever have predicted!

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# PART II

## Chapter 4

What is the complexity  
of mental healthcare and what significance  
does this complexity have for determining  
what constitutes good care?



## *The complexity of mental healthcare*

Conventional science, based on reductionism and determinism, excludes the experienced complexity of healthcare professionals, whereas complexity science offers some tools to grasp experienced complexity (1). Complexity science is a science that is based on five intellectual traditions that have developed partly, coherently, and simultaneously within the complexity sciences (2). These are dynamic systems theory, systems science, theory of complex systems, cybernetics, and artificial intelligence. The line 'theory of complex systems' has in particular been used to investigate the question, "What constitutes the complexity of good mental healthcare?" (3).

## *What does complexity mean?*

There is no all-encompassing definition of complexity, but there are equivalent descriptions. Morin states that "complexity arises in part from the empirical world, from uncertainty, from the inability to be certain about everything, to form a law or to conceive of an absolute order" (4). Robert Rosen describes complexity as a property of a system that is expressed in the fact that no single 'formalism' can capture all of its properties (5). Sturmborg, adds that a complex system is defined by its relationships and interaction patterns, not by its components (6). Snowden and Boone define complexity as a situation where the relationship between cause and effect is organic and where non-linear patterns are coherent only retrospectively (7). Paul Cilliers also emphasises the distinction between complex and complicated whereby in a complex system the interaction between the different parts of the system and the interaction with the context of the system cannot be understood by analysing only the parts (8). According to Heylighen, something is complex when there are distinguishable components that are interdependent and have both distinctions and connections. He places complexity between order (where there are many connections) and disorder (where there are many distinctions) (9). In a complex situation, therefore, you cannot (as yet) identify the problem (cause) and name the solution on that basis. In a complex system or situation, one therefore has to deal with a level of uncertainty. Key concepts from the complexity sciences are interconnectedness, interdependencies, uncertainty, dynamics, non-linear causality, emergence, adaptation, self-organisation, attractors and feedback loops.

## *Is mental healthcare complex?*

A logical first question to ask is ‘what do you mean by mental healthcare?’ Does this mean mental healthcare treatment, the mental healthcare system, the request for mental health support or mental healthcare professionals? From the point of view of the complexity sciences, mental healthcare is not about individual elements but rather how several factors in a system are interrelated and interconnected. From such a point of view, there are no clear boundaries between the mental healthcare professionals, the mental healthcare system, the mental healthcare providers, the mental healthcare clients, and the mental healthcare context (10). Mental healthcare is a system. A system is “a set of fundamental relations of association and/or opposition among a restricted number of master notions—relations that command or control all thoughts, discourses, and theories” (11). Mental healthcare as a system is influenced by other systems such as politics, the economy, the labour market, science, the client movement, fellow care providers in the healthcare chain and society with its social issues (1, 12). And because of the numerous actors involved, mental healthcare is a *complex* system (12). Below are a few examples where the complexity and interconnectedness and interdependency of the mental healthcare system become visible.

### **Example 1: *Administrative Agreement Mental Healthcare as the solution for reducing costs.***

To keep the ‘volume development’ of the mental health sector manageable, an Administrative Agreement on Mental Healthcare was developed in 2012. It was signed by all stakeholders, from the Minister to the health insurers, from client organisations to the umbrella association of care providers and specific professional organisations (13). The Administrative Agreement on Mental Healthcare was seen as a linear process with a problem definition (reductionism) and a predictable outcome (determinism). The problem was the increasing costs of mental healthcare, the solution was to control the turnover cap.

At the same time, it became a ‘preferred route for parties working in the field to safeguard their interests’ (14). What started successfully as a macro-management tool soon ended up in a positive feedback loop, where factors influence each other cumulatively (9). More parties wanted to participate. By increasing the number of parties, the administrative agreement became more abstract, had less room for elaborating on conflicting interests and currently leads to insufficient desired changes (14). As the system evolved, the Administrative Agreement on Mental Healthcare was unable to evolve with it and, as a result, proved insufficiently effective.

**Example 2: *Interconnectedness and interdependencies in mental healthcare***

Despite the various Administrative Agreements on Mental Health, Dutch society is warned that the costs of care, and therefore of mental healthcare, will increase enormously. The expectation is a fivefold increase in healthcare costs by 2060 (15). The demand for care is rising, healthcare expenditures are increasing, waiting times are rising and because of limited financial resilience, there is insufficient power to change (16). In 2020, 76% of vacancies were hard to fill and there was a 6.3% rate of sick leave (17). Despite financial tightness, mental health organisations also need to invest in digital mental healthcare. The shortage in the labour market, the high demand for care and the waiting list influence the production, while the production determines the income. At the same time, the specialised mental health sector is expanding its activities – due to the need for care in the community – to include community care. The system is complex and dynamic, but seems, under the present circumstances, insufficiently adaptive to deal with this complexity.

**Example 3: *What's complex, the demand for care of the organisation of care?***

When it comes to mental healthcare organisations and the management of their affairs, the government has identified four bottlenecks that affect the management of mental healthcare (18). Firstly, fragmentation of the supply of care makes it difficult to coordinate the supply of care and address complex care issues. Secondly, there is the problem of conflicts of interest, which can make it less attractive to transfer care to another level. Thirdly, there are perverse incentives that mean investments have to be made by one party while the profits from the investments are reaped by another. Finally, fourthly, there are the partitions between the various care services, whereby funding does not follow the client, which means that continuity of care in peaks and troughs cannot be sufficiently streamlined. The necessary bottlenecks were also identified from the client's perspective. The group of people with chronic mental health problems in particular experience difficulties in accessing care (too many service desks and different interpretations of the law), limited freedom of choice in complex requests for care, a great deal of uncertainty about the continuity of care in relation to funding, the shortage of suitable care, and finally the responsibility for care is placed with the client while the client is unable to take or bear this responsibility (19). The emphasis on disorder-oriented guidelines, which are based on single disorders and thus do not take into account comorbidity and related social problems, have contributed to the difficulty of finding care for multiple and complex problems. The question is, however, whether the problems of patients are fundamentally complex or whether the demand for care is complex to *address* these problems due to the linear way mental healthcare is organised.

Although the above-mentioned issues are not *evidence* of complexity, you may wonder if what we are dealing with here, are they complicated problems, where cause and effect can be determined from knowledge and analysis (linearity), or whether the system is complex, with a great deal of interconnectedness and interdependencies (non-linearity)? However, the Dutch Health Care Authority is (still) confident that the implementation of the care performance model will solve many problems. “The care performance model solves many bottlenecks in current funding” (20), in the same way that the government had confidence in the resolving power of the Diagnosis Treatment Combination in 2005 and later the Diagnosis Treatment Combination Towards Transparency in 2012. Are there other ways to deal with these issues? Is the time right for another suitable scientific paradigm (21)?

### *How to deal with this complexity?*

Wicked problems could (or even should) be an invitation to take a different approach, an approach based on the complexity of the system. The linear path of problem-solving should be limited to simple or, at most, complicated problems (7). But in complex problems, one should look at the dynamics of the system, at which feedback loops maintain an undesired situation, and look for feedback loops that support the desired situation. Which values drive and reward the system to evolve in this way and/or keep it this way? As long as the values stay more or less the same (economic values for instance) and the room for self-organisation is limited, social capital cannot be used sufficiently (22). In a complex situation, it is important to strengthen the adaptive capacity of the system to address its challenges. A complex adaptive system (CAS) contains characteristics to deal with this complexity, such as adaptation, self-organisation and collaboration (23–25). One of the characteristics of a CAS is that it creates emergence, i.e. unpredictable behaviour of the system (26). This emergence, combined with self-organisation and learning capacity, is very valuable for finding a balance between negative and positive feedback loops (27, 28). Self-organisation is necessary for response to various internal and external disturbances and conflicts (9). The adaptive capacity of the system and the possibilities that actors have to optimise the system through self-organisation and cocreation allow the system to adapt to unexpected situations (29).

Designing organisations as a CAS is no easy task for healthcare administrators. Traditional models of a healthcare organisation are based on breaking the organisation down into manageable units to simplify complexity as much as possible and thus deny the dynamics (30). But in complex dynamic systems, one should be aware that output also provides input for follow-up activities. These feedback loops describe an interdependency over time. What happened in the past, feeds in and effects what

happens now. What happens now will feed in and effect the future (compounding effect). Unfortunately, most people do not like uncertainty (4) and only see what they are focused on (31, 32). However, the results of current scientific research on mental healthcare are seen and valued as truth, although uncertainty is quite normal in the mental health sector. Pomare et al. (33) present three categories of uncertainty which are interconnected and interdependent. The first category is *scientific uncertainty*, with uncertainty about classifying symptoms to abstract criteria (diagnosis), uncertainty regarding the longevity of disease (prognosis), uncertainty regarding the cause of illness (causal explanations), and uncertainty regarding the best mode of treatment (treatment recommendations). The second is *practical uncertainty*, with uncertainty because of the absence of clarity regarding the expectations and responsibilities of a particular healthcare position (the structure of care), the uncertainty of the procedures one must take to access care, and uncertainty because of the lack of clarity in system guidelines. Third, there is personal uncertainty regarding the effects of illness or treatment on relationships (communicating uncertainty), regarding effects of illness or treatment on life goals and the quality of life and regarding inconsistency between the values/morals of the self, socio-cultural codes of society, the healthcare system, and/or the organization. Accepting these uncertainties is not a failure of science, on the contrary, it is a fundamental feature of the development of science: being curious and eager to learn.

For a complex adaptive system, collaboration is an important core element. A Knowledge Translation Complexity Network Model (KTCNM) can assist the understanding of the connections, communication, and collaboration necessary to promote knowledge mobilisation (34). To transform existing formal systems into cooperative networks, a good information infrastructure is needed (27, 35). “We require ongoing conversations and several ways of sense-making to understand and respond to the dynamics arising from the systems’ self-organizing properties which require ongoing learning” (36). The five elementary characteristics of a learning organisation would fit in well and are known to a broad target group (37, 38). They are: a shared vision, mental models, team learning, personal mastery and system thinking.

In summary, mental healthcare is a complex and dynamic system that is interdependent and interconnected with various other systems. To cope with this complexity, adaptive capacity needs to be increased. This can be done by taking emergence seriously, by promoting co-creation at the same time as providing space for self-organisation. For doing so, the core values of the system should fit. When the most important values are cost control and distrust of mental healthcare professionals and/or providers, the system will be in a mode of function that will ‘guard’ these values. Alternative solutions to the same problem will therefore have only limited power. Collaboration and/or co-



creation – as the core values of a system – should be made a top priority within the system, reducing the need for hierarchical structures (21,39).

*What are the consequences of accepting the complexity of mental healthcare for the meaning of good care?*

The complexity of mental health is reflected at all levels of the system. A client is more than just his depression, for example, a client can also struggle with limited quality of life and with financial concerns that are interconnected and interdependent with his depression (12, 40, 41). The complexity of mental healthcare providers lies in the fact that providing mental healthcare is interconnected and interdependent with politics, the economy, the labour market, etc. (27). This complexity seems to be overwhelming and nearly unsolvable. The simplification of this complexity and the compartmentalisation of various forms of recovery and what is good care is comprehensible.

Fortunately, there are already several promising developments underway to address the complexity of good mental health. Take, for example, Huber's vision of Positive Health, from thinking in terms of disease control to thinking in terms of resilience (42). Positive Health connects mental well-being to the quality of life, meaningfulness, social participation, daily functioning and bodily functions. Using a questionnaire all factors of health can be discussed (27, 43). The results can then be made visible through a spider web and the client can then indicate what he/she wants to work on (first). Scheepers' Recovery Support Network Intake (RSNI) also fits in well with this approach (44). This RSNI also identifies the network of people close to the client and the care providers, which improves collaboration (45). When you look at recovery options more broadly, other options emerge that could aid recovery. In this way, there is less of a one-size-fits-all approach. If, for instance, a depression is interconnected with a lack of social contacts and problems with the place where someone is currently living, then building a positive relationship in the neighbourhood is at least an option to aid recovery. A psychologist can help to redirect thinking, feelings and actions, whilst a self-direction centre can support in establishing valuable contacts in the neighbourhood. Another good example that fits well with the complexity of mental healthcare is the development of the Mental Health Ecosystem (GEM). GEM is a network that seeks to bring together all the competencies and perspectives for action necessary to facilitate change, perspective and participation across the different contexts of mental suffering, in a dynamic and learning system of collaboration, based on a strong shared vision of values-based work (40,46). GEM is primarily about the concept of co-creation. What Positive Health, RSNI and GEM have in common is that the hierarchical structure of the omniscient professional has been reduced and it is recognised that no single party holds the wisdom of good care.

The psychiatrist cannot do it by himself, the self-directed centre cannot do it by itself, and neither can the client. Complex issues, which are interconnected and interdependent, require equal cocreation and proper information exchange. Logically, then, determining good care cannot come from scientifically proven effective treatment methods recorded in disorder-specific guidelines alone.

Unfortunately, good care nowadays became of more instrumental value and the debate about good care as a value in society seems to have been diluted (47). There have been endless articles published in newspapers about (lack of) good care. Research institutes and consultancy agencies have written piles of advice on how to improve collaboration and reduce costs. Each mental health institution flaunts client-centred care. However, the debate on how one vision relates to the other vision on good care is rarely held. If we take the complexity of the mental health system seriously, there are several challenges to good care. The three issues that will be highlighted are ethical monism, epistemic injustice and the social responsibility of *action*.

### *From ethical monism to ethical pluralism*

According to Berlin, there are no one-size-fits-all answers where all our thinking and actions coincide (48). There may be some basic universal values that can be identified concerning good care, but there remain plenty of values that need to be discussed and weighed based on arguments. These different values need to be approached dialogically based on respect and equality. Ethical pluralism means respecting each other's values and ways of reasoning and constantly engaging in debate and/or dialogue about conflicting values. If we fail to do this, everyone will remain seated on their monistic ethical perspective and 'do their thing' and unintentionally we will offer (too much) space to the factor of power. In a situation in which we do not explicitly create space to discuss conflicting values with each other, almost automatically the values of those who have the most power will outweigh the values of those who have the least. The values of those who barely have a voice (certain groups in society) are then in danger of being lost.

*The enemy of pluralism is monism – the ancient belief that there is a single harmony of truths into which everything, if it is genuine, in the end, must fit. The consequence of this belief (...) is that those who know should command those who do not. Those who know the answers to some of the great problems of mankind must be obeyed, for they alone know how society should be organized, how individual lives should be lived, how culture should be developed. (48).*

A situation can arise in which, for example, the health insurer defines good care from its perspective and starts telling the health professional what good care should look like (performance indicators). Or the healthcare professional may think he knows what is best for the client and may continue to hold on to his vision of good care continuing to look for loopholes in the system to be able to continue to shape their vision of good care. The client, dissatisfied with this “good care”, is then likely to be blamed for shopping around when he or she wants yet another treatment. All seek an equilibrium within the attractor(49–51).

To address the challenge of ethical monism we should emphasise the added value of ethical pluralism in which room is made for different perspectives, visions, forms of reasoning and standards and values.

### *Epistemic injustice*

Within the context of ethical pluralism, all stakeholders should be heard equally. Unfortunately, that is not always the case. Although every vision of good care more or less refers to ‘satisfied clients’, incorporating the client’s perspective on good care is not yet self-evident (52). The group of clients with a migrant background also struggle greatly to be heard and understood (53). They often have different standards and values than average standards and values, their capacity to find their way into the healthcare system can be limited and they find themselves regularly in a more marginalised position (54).

The knowledge of individual clients and/or experts by experience is a difficult form of knowledge to articulate in the current scientific paradigm. Knowledge by experience is mainly narrative, existential and critical (55). Experiential experts experience limited support from the colleagues they work with (56). Clients and experts by experience may feel inadequately heard or experience prejudice by caregivers. This phenomenon, the lack of recognition of knowledge, is what Miranda Fricker calls epistemic injustice (57). Fricker identifies two types of epistemic injustice: hermeneutic and testimonial. Hermeneutical injustice occurs when a shared conceptual framework or source is lacking, when, as it were, the words used by interlocutors do not match and/or are insufficiently understood. Language is extremely important to convey knowledge and feelings to others, to give meaning to what is said. Testimonial injustice means that there is prejudice about the person making the statement which makes what someone says be taken less seriously. Kristie Dotson (58) talks about epistemic exclusion, where groups are excluded from developing new knowledge or from adapting current sources of knowledge. The words of a client or an expert by experience are heard but then translated into theoretical knowledge and the conceptual framework of the DSM5. In this translation, much is lost,

and dissatisfaction with the working relationship between client and practitioner can be translated into resistance to treatment (59). For healthcare professionals, there is also a balance between connecting to the language of the patient and using professional language (60). In the framework of the DSM5 or the descriptions of good care, there is limited space for the voice of the client's loved ones. Consequently, they may be perceived as difficult (61, 62).

### *Good care: a task or a social responsibility?*

How do we get past epistemic injustice, when mental healthcare is dominated by instrumental thinking in which science (through disorder-oriented guidelines) is seen as determining good care? How can one provide actual space for the perspective of good care based on ethical pluralism? How can mental healthcare providers be prevented from dominating the concept of recovery in the public discourse, whilst they can only provide clinical recovery (63)? Isn't it time for action?

For Hannah Arendt, action is the only activity that goes on directly between men and corresponds to the human condition of plurality (64, 65). Arendt distinguishes labour, work and action (*vita active*). She sees these three as fundamental human activities which correspond to one of the basic conditions under which life on earth has been given to man (64). For Arendt, labour is a cyclical process that is necessary for self-preservation and the reproduction of the human species. Work, however, is a linear process with a clear beginning and end. It is what we produce, for instance healthcare, therapy, healthcare management or healthcare administration. Action is how humans disclose themselves and can distinguish themselves from others. It includes speech and actions; it reveals who you are as a human being. Through action and speech, the unique character traits of a person become apparent (66). Where labour is cyclic and work is linear, action has no clear boundaries and can have consequences that cannot be foreseen or may be overlooked. Action has no beginning or end and its consequences can change over time.

To address the challenge of determining good care, more room for action in debating good care is needed. This fits well within complexity thinking in mental healthcare. "The fact that man is capable of action means that the unexpected can be expected from him, that he can perform what is infinitely improbable" (65).

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# Chapter 5

## Complexity of Primary Care Psychology: Theoretical Foundation

Smit EH, Derksen JIL. The Complexity of Primary Care Psychology: Theoretical Foundations.  
Nonlinear dynamics, psychology, and life sciences. 2015;19(3):269–84.



## *Abstract*

How does primary care psychology deal with organized complexity? Has it escaped Newtonian science? Has it, as Weaver (1991) suggests, found a way to “manage problems with many interrelated factors that cannot be dealt by statistical techniques”? Computer simulations and mathematical models in psychology are ongoing positive developments in the study of complex systems. However, the theoretical development of complex systems in psychology lags behind these advances. In this article we use complexity science to develop a theory on experienced complexity in the daily practice of primary care psychologists. We briefly answer the ontological question of what we see (from the perspective of primary care psychology) as reality, the epistemological question of what we can know, the methodological question of how to act, and the ethical question of what is good care. Following our empirical study, we conclude that complexity science can describe the experienced complexity of the psychologist and offer room for personalized client-centered care. Complexity science is slowly filling the gap between the dominant reductionist theory and complex daily practice.

**Key words:** Nonlinear dynamical systems, philosophy, psychology, theory, healthcare reform.

## *Introduction*

In 1948, Warren Weaver wrote an article about science and complexity that addressed the subjects of simplicity, disorganized complexity, and organized complexity (Weaver, republished in 1991). With organized complexity he meant problems with a sizable number of factors that are interrelated into an organic whole but cannot be handled with statistical techniques. He gave scientists a mission: “Science must, over 50 years, learn to deal with problems of organized complexity” (1991, p.540). Now more than 65 years later. How does psychology today cope with organized complexity? In this article, we briefly discuss the dominance of Newtonian science in psychology, and then we delve deeper into the complexity of primary care psychology. We describe the ontology, epistemology, methodology, and ethics of primary care psychology, using complexity science. Clearly, using complexity science in theoretical psychology is useful to fill the gap between theory and practice.

## *Newtonian Science*

Psychology is still caught in the reductionism of Newtonian science. The physicist and mathematician Isaac Newton and the philosopher and mathematician Rene Descartes, influenced psychology materialistically by seeing the world as a clockwork mechanism. (Dolnick, 2011). One believes in a “real world” out there, an objective world, independent of our human existence. This external world, consisting of distinguishable materials, is regular, reversible, and predictable. By analyzing this external world systematically, we can find an objective representation of our external world. As the research and analysis methods are the crucial factor, the researcher with his professional (or personal) goals stays out of sight.

One goal of clinical psychological research is to understand the behavior, feelings, and thoughts of patients with mental problems. One tries to understand the complex phenomenon of psychology by reducing its individual components (Heylighen, 2006). This linear, undifferentiated way of thinking, led by the paradigm of simplicity (Morin, 2008), assumes that outcomes are in proportion to their inputs (Guastello & Liebovitch, 2009).

Experiments are done in a (assumed) controlled context, making clear distinctions between the variables used. Once observed and defined, the variables are assumed to stay the same (independently of the observant or the context) and will only change with some kind of input (intervention). The psychologist tries to uncover changes that can be objectively observed (Heylighen, 1989). Because there is an objective world to be discovered, doing this in a systematic and repeatable way will result in objective and universal knowledge.

These days, professional guidelines (research-based recommended standards for the treatment of disorders) are unthinkable without this kind of reductionism and universal determinism, where the disorder is isolated from both patient and context and is instead defined in symptoms or variables. The same principle applies to the treatment and interventions that are disconnected from the therapist. Specific factors that influence treatment, such as reactance or resistance, preferences, culture, religion or spirituality, stages of change, coping style, expectations, and attachment style are ignored (Norcross, 2011).

Psychologists dealing with experienced complexity on a daily basis are the first to feel the gap between the complexity they experience and reductionist scientific theory and professional guidelines. They know no single patient is the same and the closer the analysis of the individual experiencing process, the more the unique subjectivity is

revealed. They have a strong need to bring theory and practice together, now practically, because health insurance companies force us to work *only* with professional guidelines (that are linear and focused only on the mental disorder). As Katerndahl describes it, clinical guidelines are limited in their application and often irrelevant to the unique context of the individual doctor–patient dyad (Katerndahl, 2010). Clearly, it is of utmost importance to develop a theory regarding the daily complexity of clinical psychologists and thus help them develop their field further. In this article, we focus on the setting of the primary care psychologist in the Netherlands.

## *Complexity Of Primary Care Psychology*

*American Psychologist* (McDaniel & deGruy 2014) dedicated a special issue to primary care psychology, defining primary care as given by the Institute of Medicine:

*Primary care is the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community (Institute of Medicine, 1994).*

Primary psychological care in the Netherlands is defined as follows: “A short-term generalist treatment of a client with mildly to moderately severe, non-complex psychological problems, including the associated diagnostics.” (Nederlandse Zorgautoriteit, 2012). In 2008, basic health insurance covered the cost of eight treatment sessions, and supplementary insurance covered about another four sessions. For years the average number of sessions with a primary care psychologist has been around seven and over 70% of treatments are concluded in under eight sessions (Landelijke Vereniging van Eerstelijnspsychologen, 2005–2011). In 2012, the Dutch government reduced the number of sessions covered by basic health care insurance to five. Again in 2014, the government reorganized primary care psychology into “generalist basic mental healthcare” with four care products, Short (300 minutes) Middle (500 minutes), Intensive (750 minutes) and Chronic care (750 minutes). Health insurances insist on the use of professional guidelines and compel practitioners to present routine outcome measurements (based mainly on symptom reduction reported by the client).

Primary care psychology is seen (by others) as treating “minor mental problem,” while secondary mental healthcare (called specialized care) treats major mental health problems. The complexity of the mental problems in its context is seldom taken into consideration. Now more than ever, primary care psychology is subject to medicalization without sight of what is normal (Foucault, 1973; Szasz, 2007). According to Allen Frances, chair of the

task force that produced Diagnostic and Statistical Manual IV, we are shifting away from our natural resilience and self-healing competence (meaning, dealing with mental problems without professional help), ignoring the market-driven risk of overrating attention-deficit disorder, bipolar disorder and autism (Frances, 2013). The biomedical model is dominant at the expense of the biopsychosocial model (Sharfstein, 2005). McDaniel and deGruy (2014) assert that the biomedical model is incomplete and has significant limitations. "This method is not sufficient for understanding many aspects of complex systems, such as whole human beings, who feature emergent properties" (p. 325). Even the World Health Organization warns us of an overly one-sided biomedical perspective, in which health systems and services focus mainly on disease rather than on the person as a whole (WHO, 2007). We can no longer disregard the complex adaptive nature of the health system (Sturmberg & Martin, 2010).

The restrictions of Newtonian science in psychology, fear of ongoing medicalization and complexity of primary care psychology experienced in daily practice made us aware of the usefulness of complexity science in primary care psychology. We studied complexity science, starting with the complexity of social sciences using the work of biologists and philosophers Humberto Maturana and Francisco Varela (autopoiesis and adaptation), the French philosopher Edgar Morin and the South-African philosopher Paul Cilliers (complexity theory and epistemology). Later on, we expanded our work to include the theory of nonlinear dynamical systems in psychology to explore complexity and chaos theory as described by Guastello, Koopmans and Pincus and the Belgian cyberneticist Francis Heylighen. We combined primary care, psychology sciences, philosophy and complexity science as well as theoretical scientific research results and the experiences of primary care psychologists. Our first goal was to narrow the gap between theory (from a Newtonian perspective) and practice (from a complex system perspective). We started to develop a theory regarding experienced complexity into the foundations of primary care psychology. This means we primarily focused on the ontology, epistemology and ethics of primary care psychology (without quantifying the complexity of behavioral patterns using mathematical models). This research project was co-created with experienced primary care psychologists.

Primary care psychology developed organically. After more than 30 years of experience, robust core features of the primary care psychologists can be identified (Derksen, 2009). The treatment of primary care psychologists has been monitored for more than ten years (Prins, Verhaak, Smit, & Verheij, 2012; Verhaak, Kamsma, & van der Niet, 2011). In 2008, the professional competences of the primary care psychologists were defined and additional training was developed. The present study linked all these experiences and data to the complexity theories.

The next section briefly describes the ontology, epistemology, methodology and ethics of primary care psychology as essential components of the description of the foundations of primary care psychology. We distance ourselves from the Newtonian way of thinking and focus on complexity science as a contrasting perspective.

## *Ontological Complexity and Primary Care Psychology*

Ontology means the way we see or define “reality” as the being of being. One assumes a reality independent from and prior to human cognition.

*For centuries, the world-view underlying science has been Newtonian. The corresponding philosophy has been variously called reductionism, mechanism or modernism. Ontologically, it reduces all phenomena to movements of independent, material particles governed by deterministic laws. (Heylighen, 2006, p. 18).*

*Ontological issues concerning complexity science are related to the nature or defining properties of entities, especially concerning their organization structure and relations with other entities (Kunneman, 2010).*

*Something is complex in the ontological sense (disregarding whether we can know it completely or not), when it is organized as a system of many non-identical components who themselves have systems-like properties (such as being further decomposable), and whose mutual interactions bring forth a kind of collective behavior which is different from the behavior of the parts. (Emmeche, 1997 p. 43).*

From the perspective of the primary care psychology, we are not looking for definitions of what *is* (the ontological question) but are focused on relationships between dynamic systems. Cilliers (1998) argues that emergence emerges from the complexity of internal interactions in systems. There are no clear boundaries, he says, between one system and the other or between the system and its environment. According to Cilliers, boundaries are simultaneously a function of system activity and a product of the strategy description involved (Cilliers, 2005). Constructs like the brain or a disorder are just products of the observations. We should not look for master keys within complex systems but pay attention to complex self-organizing interactions and patterns that perpetually transform the system as well as the environment in which it operates (Cilliers, 1998). Every system has an abstract boundary and its own environment. Information is exchanged continuously between the system and the environment. When there are regular input-output relations, one can speak of a network (Heylighen, 2006).



According to Doll and Trueit (2010) there is no definition of the real world. The world we live in is complex, each situation has unique qualities.

Primary care psychological treatment addresses problems with a lot of contributing factors that are interrelated into an organic whole, but cannot be handled with an approach that is oriented too much on ordinary statistical techniques. Human cognitive capacity is often too limited to grasp all the dynamics of related systems. There is too much uncertainty (Prigogine & Stengers, 1997). People would rather look for patterns that reduce the complexity to a few indicators (symptoms of disorders; Pieters, 2010). To transform practice we need systems thinking and acting and to harness powerful connectivity between components and to bring about patterns of change and learning rather than fixed solutions and final answers (Peek, Cohen, & deGruy 2014, p. 438).

### *Epistemology: What Can We Know About Primary Care Psychology?*

Epistemology is the study of knowledge and justified belief. What are the necessary, sufficient conditions of knowledge? What are its sources? What are its structure and limits? (*Stanford Encyclopedia of Philosophy, 2015*).

*All knowledge operates through the selection of meaningful data and the rejection of data that are not meaningful. It does so by separating (distinguishing or disjointing) and unifying (associating, identifying), and by organizing into hierarchies (the primary, the secondary) and centralizing (around a core of master notions). These operations, which use logic, are in reality driven by "supra-logical" principles of organization of thought, or paradigms: the hidden principles that govern our perception of things and of the world, without our being conscious of them (Morin, 2008, p. 2).*

Bruno Latour, a French sociologist of science wrote an influential book called *Science in Action* (Latour, 1986, 1987). Although he seldom specifically mentions dynamics or complexity science, his book is all about emergence in scientific research, in which knowledge and knowing have no strict boundaries. He claims that "reality" cannot be seen in a laboratory. He describes how scientific discoveries "emerge" from working together. Prigogine & Stengers argue that our scientific knowledge of the world is fundamentally uncertain (Prigogine & Stengers, 1997). The whole is more than the sum of its parts... Emergence cannot be predicted or seen beforehand. Health is an emergent property that is greater than the sum of its components (Katerndahl, 2010). The knowledge (of primary care psychologists) is a subjective construction, not an objective reflection of reality.

Concerning epistemological view, close attention is paid to the relation between the knowing subjects and objects of knowledge (Kunneman, 2010). The patient cannot be reduced to their disorder and the therapist cannot be seen as an objective instrument. In treatment, the dynamic systems surrounding the patient interact with the dynamic systems surrounding the primary care psychologist. The general practitioner's referral – necessary for reimbursement – interacts with the (start of the) treatment. Even when professional guidelines are followed strictly, the appearance of emergence is inevitable and therapy outcomes are therefore unpredictable. Every patient is different and every slight variation can produce a dramatic change (Lorenz, 1993). Therefore, we stopped striving for certainty and accept uncertainty and ambiguity (Doll & Trueit, 2010).

Primary care psychologists call on several sources of knowledge (psychological, social–economical, moral knowledge and practical experience). They use professional guidelines to enrich their knowledge but simultaneously incorporate knowledge about social–economic issues and patients' values and meaning. The art of primary care is to combine different sources of knowledge, and then judge and apply them in relationships with the patient. This demands a certain professional freedom and a need to justify the choices made.

Sturmberg and Martin (2008) argue that knowledge in health care is not objective and static, but a multidimensional dynamic construct. They state that “complex adaptive systems science views knowledge simultaneously as a thing and a flow, constructed as well as in constant flux” (p.767). In their article “Complexity and health – yesterday's traditions, tomorrow's future.” Sturmberg and Martin (2009) also elaborate on the distinction between simple problems, complicated problems, complex problems, and chaos on the one hand; and what can be known on the other hand. The cause and effect relations of simple problems are repeatable, perceivable, and predictable. This is what can be known. The cause and effect of complicated problems are separated over time and space. They are not easy to know but still knowable. With proper reasoning and research we can identify their logical relations. Complex problems, however, fall in the category of “unpredictable” and can only be known (in broad terms) afterwards. Chaos means that no cause and effect relationships are perceivable, and is thus by definition unknowable. We may *think* we know because we have seen this before, but that is because humans tend to think in terms of cause and effect, and the more they experience certain occurrences following each other, the more easily they are convinced that there is a causal connection between them (Hume, 1978).

Our focus is, therefore not on “knowing the patient's problems” and having “knowledge” about mental disorders and ways of treatment. After all, our intention is not to define mental disorders but to intervene in the direction of a desired, feasible new

equilibrium that is personal and contextual, and cannot be universal defined. Personal meaning always takes one into account and cannot be universally formulated (Cassell, 1982). We respect the patient's own evolutionary trajectories (Heylighen, 2006).

### *Methodology: How To Act In Primary Care Psychology?*

The main question of the first treatment session is, "Why is this patient, with these problems and this request for help, with me, right now?" The primary care psychologist does not heal the patient simply by relieving the symptoms of the disorder according to current professional guidelines or best practices. The mental problems of the patient, as presented to the psychologist, portray a view of the dynamics of the patient's life. Sometimes life requires more mental skills than one has acquired. Sometimes the patient has an inadequate coping style. In other cases the patient is stuck in a pattern that is not suitable for the current situation. The psychologist analyses the relations and interactions of related systems to understand the dynamics, and explores adequate and appropriate interventions to reach a feasible equilibrium. The focus during treatment is on health (not the disease), social participation (family, social activities), and resilience. Resilience can be defined as "the ability to respond to a perturbation by either becoming rigid and robust, or flexible and fluid without becoming stuck or falling apart respectively" (Pincus, 2010, p. 9). The response to perturbations can be stimulated by acknowledging the ability to self-organize.

Primary care psychologists make use of the patient's tendency to self-organize, or in other words, the ability of patients to organize global structure out of local interactions (Heylighen, 2008). Self-organizing systems are capable of change, adaptation, and growth and can be related to the resilience of the patient (Pincus, 2010). "Most symptoms have the potential to decrease fitness locally and temporarily (e.g. pain or fever), while at the same time serving to preserve the structural connectivity of biopsychosocial systems during illness." (Pincus, 2010, p. 360). Positive feedback can lead to growth until all components have been absorbed into the new configuration. Negative feedback (if the reaction is opposite to the initial action) can stabilize the system by bringing deviations back to their original state. (Heylighen, 2001, p. 10).

The primary mental health care context and the embedding of the primary care psychologists in this context determine the psychologist's attitudes (Derksen, 2009). This attitude is integrated in the biopsychosocial model of health and disease with specific attention to such aspects as health promotion, illness prevention, and cure (Borrel-Carrió, Suchman, & Epstein, 2004). In this model, health does not equate to absence of disease but is accompanied by good quality of life and strong relationships.

Viewed from this perspective, health promotion, diagnosis, and treatment lie along a single continuum. The goal of the treatment is to move into the direction of a feasible and desirable equilibrium (not solely symptom reduction), using the patient's resilience as well as possible, and self-reliance and participation as important pillars. In a healthcare system, where great emphasis is placed on measuring care results and working with universal professional guidelines, primary care psychologists put much effort into making space for the dynamics of mental healthcare. For instance, instead of starting treatment based only on a classification or diagnosis of the mental problems of the patient, the need for help is weighed with the help of a matrix (Table 1).

This matrix gives space to the dynamics between: (a) the presence of axis I/II disorder (or cluster traits) according DSM-IV-TR, (b) the daily level of (dys)functioning, (c) the extent of the request for help, (d) the patient's communicative and/or relational competences, (e) the patient's learning ability and (f) contextual factors. The presence of axis I/II disorder (or cluster traits) legitimize our giving psychological care, as intended by health insurance law. Gauging the patient's daily level of (dys)function demonstrates our focus on client-oriented (instead of disorder-oriented) care, as has been done for the last 30 years by primary care psychologists in the Netherlands.

The patient's communicative and relational competences and learning ability are transcending concepts of specific factors that influence treatment. Finally, the contextual factors represent the system dynamics and interaction with other relevant systems.

**Table 1. Mental Problems Matrix for Primary Care.**

Presence of axis I / axis II disorder (or cluster traits)	Level and seriousness of disorder and/or cluster traits are minimal.	Level and seriousness of disorder and/or cluster traits are complicated.	Level and seriousness of disorder and/or cluster traits are complex. There are several disorders / cluster traits.
Seriousness of the symptoms	The symptoms are obstructive but not dominant.	The symptoms are obstructive and influence one's thinking on a daily basis.	The symptoms are obstructive and are observed dominantly on a daily basis.
Level of daily (dys)functioning	Daily functioning is sometimes hindered.	Daily functioning is regularly hindered.	Daily functioning is restricted.
Extent of the request for help	There is a singular request for help and the request for help is identified by the client.	The request for help is multiple or diffuse.	The request for help is complex and/or acute.

Learning ability	Learning ability in relation to the request for help is sufficient.	Learning ability in relation to the request for help is limited.	Learning ability in relation to the request for help is poor.
Contextual factors	Contextual factors may play a positive role.	Contextual factors are insufficiently clear and/or neutral in relation to the recovery.	Contextual factors play a negative role in the recovery and/or the treatment.

Each item can be scored at three levels, ascending in terms of severity and complexity. This matrix can make clear that patient A with depression will need perhaps only three sessions (because the patient has a supportive partner and a singular request for help), while patient B with depression needs eight sessions (the patient has restricted functioning and limited learning ability). The matrix illustrates our focus on the relationship between all items.

The primary care psychologist uses Ashby’s Law of Requisite Variety, where the variety of the regulator must equal the variety of the system. If a complex system has to take “control”, the number of states of its control mechanism must be greater than or equal to the number of states in the system (Ashby, 1958). Ashby connects variety to information. Requisite variety implies that one needs a certain amount of information to “control the system.” Only when there is enough information about a system can one control it. When the system has hidden properties and knowledge about it is limited, however then there is uncertainty about the behavior of the system. Translated to primary care psychology, primary care psychologists deal with a highly diverse patient population. The psychological problems also vary greatly in severity, extent, and duration. Since primary care psychologists do not have all information about the patient (as a system) and they cannot fully control the system. They can however use an extensive toolbox with a wide variety of psychological interventions. “Only variety can destroy variety” as Ashby says (Ashby, 1956, p. 207). Using a wide variety of psychological interventions contradicts professional standards which mostly prescribe cognitive behavior therapy.

Primary care psychologists are trained to intervene between order and disorder, knowing that these are two sides of the same coin. When a patient is stuck in a “dysfunctional” behavioral pattern, the psychologist can introduce some chaos. When the patient’s life is (too) chaotic, stability is offered. The psychologist is challenged to find negative or positive personalized feedback loops to orientate the patient. There is no linear process of cause and effect. The situation is a circular causality with perturbations. To cope with these perturbations the psychologist can offer control mechanisms such as:

- (a) *Buffering*: The psychologist ensures that the perturbation is reduced or absorbed. (b) *Feed forward*: The psychologist anticipates any perturbations; perturbations are compensated with interventions before they can affect the goals. (c) *Feedback*: The psychologist's compensatory interventions restore the patient's course toward the required (feasible) equilibrium.

### *Ethics: What Is Good Primary Psychologist Care?*

When it comes to the ethical question *how to define good care*, at least two sources are helpful in answering this question. First there is the ethical code of healthcare professionals that describes the ethical environment and attitude of care professionals. Secondly, nowadays more predominant, there are the demands of healthcare insurers related to providing good care. Insurers demand quantitative data on care results and compel psychologists to work strictly according to the professional guidelines. How can the primary care psychologist function in an environment where professional discretion is paralyzed by protocol and professional guidelines that reduce complex care issues and complicated problems to simple solutions? This is a major challenge! The primary care psychologist must therefore be a *craftsman*. Craftsmanship means having the skill to make things better, not just because "that's what needs to be done," but as an intrinsic desire to do a job well for its own sake (Sennett, 2008).

*Every good craftsman conducts a dialogue between concrete practices and thinking; this dialogue evolves into sustaining habits, and these habits establish a rhythm between problem solving and problem finding. (Sennett, 2008, p. 9)*

Craftsmanship is about the dynamics between finding and solving a problem, where solving the problem leads to another type or level of problem. This can be seen as a dynamic learning process. Sennett demonstrates that conditions must to be met for craftsmanship, such as "freedom from means–ends relationships" (Sennett, 2008 p. 288). This connects to the kind of freedom mentioned in the section on epistemology. How do you deal with the tensions between reductionism and complexity, and between care according to protocol versus professional discretion? Firstly, it helps to recognize the differences between simple, complicated, complex, and chaotic situations. Secondly, we are aware of the dynamics in health care, as described closely in Ian Hacking's looping effect in "making up people" (Hacking, 1986, 1998, 1999). Meaning when a disorder is defined, patients with this disorder will be found. Thirdly, we plead for ethical pluralism. Ethical pluralism involves respect for other's values and way of reasoning, and continuous debate and dialog about conflicting values. Isaiah Berlin, a social and political philosopher, claims that values are creations of mankind,

rather than products of nature waiting to be discovered (Berlin, 1998; Cowden, 2004). Berlin preferred an ethical pluralism in which moral values can be equal, but might come into conflict with each other. Our interest is in how several ethical theories interact with each other. For instance, what is the dynamic between ethical theories such as deontological ethics, virtue ethics, pragmatic ethics, and how does our vision on good care develop? Should it, in the end, be the context (and the dynamic) of the conflict that is crucial to what “good (care)” is?

There is no objective *good care* that can be described in a linear guideline. Morin suggests that we abandon “programs” and invent new strategies (Morin, 2008). Morin places “strategy” in opposition to “program.” With a program you decide what to do, devise a protocol for how you want others to act, make your targets SMART (Specific, Measurable, Assignable, Realistic and Time-related), and so on. However, according to Morin, strategy battles against chance and seeks information. Here there is room for the dynamics of mental health care and for craftsmanship. Strategy takes advantage of chance, and seeking information is inherent to development.

### *Vignettes Study*

To gain more insight into the complexity of primary care psychologists, we used empirical data collected in 2010/2011. At the end of 2010 and beginning of 2011, some 30 psychologists followed an eight-day course entitled “The Science of Primary Care Psychology” (given by the authors), including training days on complexity sciences, social issues and mental health, normative professionalism and ethical diversity. During this course, 23 primary care psychologists wrote 113 vignettes on “complexity experienced in practice.” The instruction was to write a few (3–5) vignettes describing the complexity they experienced in the office in daily practice (see sample vignette, below). The psychologists described the situation, their emotions, the associated (social and professional) norms and values and some also analyzed the tension between several levels of knowledge. These vignettes gave us an interesting insight into the everyday complexity of primary care psychologists (not yet published). One example of our vignette is as follows:

*Patient (m) is severely depressed. Partner comes along to the first session; she is very disappointed in her husband. He is not a good father – she says – he often yells at the children. Patient seems burned out, has no energy for anything. The medical officer thinks the patient is faking his depression and wants him back at work as soon as possible. There is a tension between the immediate demands of the medical officer and the wife. Both seem to maintain*

*the situation instead of supporting the mental health of the patient. Patient seems in need of some distance and the time to become more assertive.*

## Method

For this article, we analyzed the vignettes looking for how many and which open systems were involved. We defined a system as “a set of things working together as parts of a mechanism or an interconnecting network; a complex whole” (Oxford Dictionary). Morin defined a system in terms of a paradigm, as “the set of fundamental relations of association and/or opposition among a restricted number of master notions—relations that command or control all thoughts, discourses, and theories” (Morin, 1992, p. 372). Our research design was based on Greene’s *mixed methods in social inquiry* (Greene, 2007), which involves a plurality of philosophical paradigms, theoretical assumptions, methodological traditions, data gathering and analysis techniques, and personalized understanding and value commitments.

*A mixed methods way of thinking aspires to better understand complex phenomena by intentionally including multiple ways of knowing and valuing and by respectfully engaging with differences, both those presented by other inquirers’ mental models and those located in the social world (Greene, 2007 p. 17).*

We defined and coded five relevant systems in this vignette study: (a) *patient* (including personal context such as their family), (b) *psychologist* (including professional context such as their office and coworkers), (c) *healthcare* (including insured and uninsured healthcare, referrals and care funding), (d) *society* (including social demands, norms and values) and (e) *ethics* (meaning, ethical principles and normative choices related to good care). First, we looked at how many systems were mentioned per vignette. Second, we looked at what kind of tension was described in all the mentioned systems per vignette. Our goal was to show that the qualitative good psychological treatment of mental problems involves more than a well described psychological treatment and well described mental problems. The mental problems of the patient are often related to relations with persons in their personal context, social pressure or demands and also the health systems play a role in the relation between the psychologist and the patient.

Two researchers separately scored the vignettes and the differences between the scores were discussed. We chose to leave the differences between both researchers intact, basing the decision on our view that when conducting research from a complexity perspective, the outcome is not clear cut science (or humdrum routine).



## Results

On average 2.82 (0 – 5) systems were described per vignette. *Psychologist* (system) was mentioned most often, 92.92% (researcher 2) and 96.46% (researcher 1), not surprisingly, because psychologists wrote the vignettes. The second most described system was *ethics*. Doubts, worries and irritations about the question “what is good care” predominate in this category which also showed a significant difference in score between researcher 1 (45.13%) and 2 (61.06%). This can be explained by the fact that researcher 1 is also an ethicist (such differences can be seen as normal bias, although these are rarely published). Third, *patient* (system) was the most involved, 28.31% (researcher 2) and 35.39% (researcher 1). We expected that *healthcare* (most mentioned in public debates about tensions in practice) would be the second most mentioned tension, but it scored fourth with 29.2% (researcher 2) and 30.08% (researcher 1). The same applies to *society*. Although almost every vignette mentioned social issues (problems of loneliness, the social pressure of “being useful and successful in life”, emotional overload), only in 15.92% (both researchers) of the vignettes was society one of the core systems. The average number of systems scored in this part of the study was 2.23 (researcher 1) and 2.27 (researcher 2). The most frequently mentioned tension in the vignettes was between “the psychologist and ethics”, followed by “the psychologist and the patient” and “the psychologist and the healthcare system.”

We described earlier that most studies in psychology try to understand the behavior, feelings and thoughts of patients with mental problems by reducing all systems involved into individual components. Input (psychological treatment) is expected to be in proportion with its outcome (symptom reduction). With this vignette study we illustrate that the focus of primary care psychology is – at least also – on the relation between dynamic systems (ontological complexity). Primary care psychologists have to combine several sources of knowledge (epistemology) like knowledge about psychology, ethics, social issues and laws and rules linked to our healthcare system. The patients’ mental problems – as described in the vignettes – have no clear cause and effect relationship. Per example when two or more open systems are involved, interaction between open systems is highly plausible. Development of an open system is difficult to predict, which is further hampered if several (2.82 on average) open systems interact with each other. The common notion that care delivery based on professional guidelines (scientifically proven effective methods) always works and is effective regardless of context is at odds with the results of our study.

### *Critical Remarks*

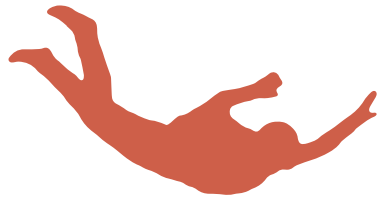
Complexity science fits well with the daily practice of primary care psychologists. Current descriptions of primary care psychology are mainly based on statistical data; the field lacks a meaningful and useful theory (Derksen, 2012). Complexity science is however not *the* answer to all problems in primary care psychology. In this sense, it is no “better” than classical Newtonian science. And yes, complexity science is abstract and hence somewhat vague. It does, however, offer a new perspective. It gives hope to tackle unsolved (and ignored) problems in primary care psychology and it gives words to the experienced complexity of the psychologist and room for personalized client-centered care. It narrows the gap between reductionist theory and the complexity of daily practice. In this sense, we find complexity science – in primary care psychology – very promising. However, Weaver’s mission remains unfinished.

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# Chapter 6

## Vignette Research on Messy and Confusing Problems in Primary Mental Healthcare

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## *Abstract*

The average primary care psychologist feels an ever-widening gap between objective, measurable reality as described and the complex and dynamic reality they experience. To obtain a better understanding of this complex dynamic reality, we conducted an exploratory mixed-method study of primary care psychologists. We asked our participants to write vignettes about messy and confusing problems in the complex context of mental healthcare. We then examined the data in portions, exposed the patterns in the data, and subsequently analysed all in conjunction. The 113 vignettes showed experiences of psychologists dealing not only with the patient, but also with the family of the patient and/or employers, working together with other healthcare professionals, struggling with dilemmas and having mixed feelings. However, using the Cynafin Framework, 36% of the vignettes were still rated as simple. Was it because those vignettes contained fewer words ( $p = .006$ )? Or because it is difficult to grasp complexity when cause and effect are intertwined with emotions, norms and values? In the discussion, we suggest examining a complex dynamic system in terms of both the consistency of its various elements and the dynamics of the system. We also discuss how to optimize the system's adaptive self-organizing ability and how to challenge ourselves to invent negative feedback loops that can keep the complex system in equilibrium.

**Key words:** Complexity theory, vignette study, primary care psychology, complexity, mixed-method study.

The complex daily reality of healthcare that psychologists experience is influenced by numerous factors. Every day, care professionals evaluate and assess available information and its relevance to their actions. During their training, they learn to classify this complex reality into uniform categories, for example as symptoms of a mental disorder. Factors that do not fit a disorder are mostly ignored. Increasingly, both students and care professionals are trained to follow protocols aimed at output rather than at handling complex and dynamic situations (Derksen, 2015).

The psychological literature seldom includes any mention of chaos. Research only includes factors that are measurable according to a rigid order and a well-defined method. Then results are guaranteed and hypotheses can nearly always be confirmed (Fanelli, 2009; Fanelli, 2012). Science hardly addresses the fact that observation, as a method, is in itself a psychological process leading to changes in the mental patterns studied (Derksen, 2015). Government policy and descriptions of good care formulated by care financiers also have little room for complexity and chaos. To them, care can be objectified, rules can be applied to the care system and the results of care can be measured.

When science, the government and healthcare training programmes consistently focus on reducing the experienced complexity, care professionals are encouraged to do the same. But then, what are we to do with messy and confusing problems in the complex and sometimes even chaotic context of mental healthcare?

The average care professional feels an ever-widening gap between objective, measurable reality as described and the complex and dynamic reality they experience. Every day, care professionals face messy and confusing situations for which there are no disease-oriented guidelines, where the rules of the care system are not enough to hold on to, where care results cannot be assessed with routine outcome measurement tools and where 'good care' is open to many interpretations. To obtain a better understanding of this complex dynamic reality, we conducted an exploratory mixed-method study of 23 primary care psychologists. Our research question was 'what patterns can be analysed from vignettes describing messy and confusing problems in the complex context of mental healthcare?' To prepare for the study, we conducted a literature study on the gap between objective, measurable reality as described and the complex and dynamic reality psychologists experienced.

### *Messy and Confusing Problems*

The gap between objective and measurable reality and reality experienced as complex and dynamic is a familiar phenomenon. The German philosopher Jürgen Habermas described the distinction between the world as a political and economic system, on the one hand, and the world people live in on the other (Habermas, 1968). The French philosopher Bruno Latour showed that even in the world of objective and measurable reality, complex social problems play an important role (Latour, 1987). Much has also been written about coping with this gap and the competences required to do so.

Michael Polanyi made a significant contribution to the discourse on tacit knowledge. Tacit knowledge can be defined as knowledge and skills which professionals are less aware of having but which nevertheless direct their actions, transcend the generally available scientific knowledge and are necessary in day-to-day practice (Polanyi, 2009). Aaron Antonovsky added the concepts of 'sense of coherence' and 'self efficacy' to this discourse. Sense of coherence can be defined as the ability to connect the comprehensible and the incomprehensible (Antonovsky & Sagy, 1986). The concept of self efficacy can be defined as the ability to act meaningfully in the world around you (Ibid).

The American philosopher Donald Schön describes objective and measurable reality and reality experienced as complex and dynamic in terms of 'high hard ground' and

'swampy lowlands': "On the high ground, manageable problems lend themselves to solution through the use of research-based theory and technique." (Schön, 1995, p. 27). He contrasts this with the swampy lowlands, the unruly day-to-day reality. "In the swampy lowlands, problems are messy and confusing and incapable of technical solution" (Ibid).

On the high ground, all mental symptoms that patients exhibit either fit or do not fit the DSM (American Psychiatric Association, 2013) criteria for mental disorder. On the high ground, it is assumed that a scientifically unverified method cannot (yet) be effective and successful. The same is true for quality of care, where the *argumentum ad ignorantiam* fallacy applies: you must prove that your work is of high quality; otherwise, it is of insufficient quality. How different are the swampy lowlands, the day-to-day reality of psychologists, in primary care and elsewhere. The swampy lowlands contain far more than just mental symptoms and diagnosed disorders but also, for example, obstinate patients with complicated personal circumstances and colleagues who have a very different view of good care. There, social and societal problems play roles in the consulting room and even professionals can be led by their emotions. At issue are equivalent but conflicting values that have no easy answers....

## Vignette Study

### *The Context*

To obtain a better understanding of the complex dynamic reality of psychologists, we conducted an exploratory mixed-method study. With our study, we attempt to 'translate' the swampy lowlands in terms of the high hard ground. Our goal is to include the swampy lowlands in the scientific debate on mental healthcare. The first obstacle we must overcome is the question of how to 'capture' these swampy lowlands in a scientific article.

We started by asking Dutch primary care psychologists to write vignettes, which would make the swampy lowlands apparent. In 2011, 29 experienced primary care psychologists followed an eight-day course entitled *De wetenschap van de eerstelijnspsychologie* [The science of primary care psychology]. This course covered the scientific foundation and societal context of primary care psychology, the normative professionalization of primary care psychologists, the complexity of the work of primary care psychologists, and various research fields of primary care psychology. The course day covering the normative professionalization (Kunneman, 2005) of primary care psychologists focussed on professional and personal accounts of messy and confusing problems in daily practice. The course day on the complexity of the work focussed on the dynamics in daily practice and the fundamentals of complexity sciences. The participants shared experiences, discussed

moral dilemmas and obtained a better understanding of the normative nature of their professional conduct. The homework assignment was to write three to five descriptive vignettes of messy and confusing problems in their work. Of the 29 participants, 23 completed the assignment, writing in total 113 vignettes.

### *Sample Vignette*

*The client is a young man (31), married, father of two young children and employed by a medium-sized accounting firm. His work is of a very high standard. He has been on sick leave for ten weeks now, with symptoms of fatigue, frequent headaches, hand tremors and a general sense of being unable to meet the quantitative demands placed on him. The occupational health physician has 'ordered' him to resume work for three days, two hours a day. The client states that he can hardly cope with this. During our sessions, the client's lack of confidence and fear of failure clearly come to the fore. Other issues that must be addressed are his difficulty with establishing boundaries and standing up for himself.*

*After three weeks, his superior tells him that he must start working five days a week, two hours a day. When the client says he is not ready, his superior consults the occupational physician and then tells the client that the doctor agrees that he is ready to work more hours and that's the end of it. On his next appointment with the occupational physician, the client tries to explain that he really is unable to work more hours yet. The doctor says that he feels the client is not giving him good enough arguments and sees no reason to change the new workload, and that if 'the psychologist' disagrees, he should phone him.*

*The client phones the psychologist and asks him to contact the doctor to explain why he cannot work more hours yet. The psychologist promises to do so. However, after this conversation he begins to doubt whether that is the right thing to do.*

This vignette was written by one of the participants of the vignette study.

### *Research Design*

For the theoretical background, the researchers were guided by various theories. Firstly, an interest in complexity sciences. Complexity science fits well with the unruly day-to-day reality of primary care psychologists (Smit, 2015). There is no formal definition of complexity sciences but this emerging approach to research can be seen as a

collection of theories and conceptual tools (Benham–Hutchins & Clancy, 2010; Paley & Gail, 2011). It can be described as the scientific study of complex systems, in which many parts interact. This vignette study is a part of a larger study on the complexity of mental health care.

Secondly, the researchers used the mixed methods in social inquiry approach outlined by Greene (Greene, 2007). “Mixed methods social inquiry involves a plurality of philosophical paradigms, theoretical assumptions, methodological traditions, data gathering and analysis techniques, and personalized understanding and value commitments [...]” (Greene, 2007, p. 13). It “aspires to understand complex phenomena by intentionally including multiple ways of knowing and valuing and by respectfully engaging with differences, both those presented by other inquirers’ mental models and those located in the social world” (Greene, 2007, p. 17).

Finally, we applied the qualitative research aids provided by Braun and Clarke (Braun & Clarke, 2013; Braun, Clarke, & Terry, 2015). Following Braun and Clarke we included three kinds of question used in qualitative research. The first concerned our research question: ‘What patterns can be analysed from vignettes describing messy and confusing problems in the complex context of mental healthcare?’ The second was for the participants, the authors of the vignettes. They were asked to describe three to five instances of messy and confusing problems they experienced as complex. This question was posed in the context of the eight–day course ‘The science of primary care psychology’ described above. The third question dealt with how we worked with our data. They varied according to the portions of the vignette and will be further explained below.

The vignettes were written according to the following structure. Participants described the *context*, the setting in which the situation occurred. They described the *situation*, the ‘core’ of the vignette (see example above). They included the *emotions* involved in the situation – which could be what the psychologists themselves, the clients and/or other parties felt – and the norms and values that played roles in the situation. These topics were selected with the participants at the end of the course days on normative professionalization and the complexity of the work. Our research design took a semantic approach to all data used (data corpus, Braun, Clarke, & Terry, 2015). It was decided to analyse the situation descriptions with the Cynefin Framework because of Snowden’s embeddedness in the complexity sciences (Snowden & Boone, 2007). Then the emotions mentioned in the vignettes, the persons involved, and the values were all categorized. Finally, the vignettes were checked for the presence of terminology related to professional conduct. Two researchers conducted the study. They began by reading all the vignettes several times. Coding and assessment of all aspects of the vignette was initiated jointly and then allocated to the either one of the researchers.

Researcher A first examined the situations, the people involved and the terms related to professional disease-oriented guidelines. Researcher B encoded the emotions and values. Both researchers kept written notes and discussed these afterwards. Dubious cases were discussed extensively in order to arrive at a joint decision. Researcher B sample-checked the measurements and coding of A researcher and vice versa. Again, any differences in judgement were discussed in order to reach consensus. The final analysis was done by the principal investigator (researcher A) and discussed with researcher B and the authors of the vignettes.

### *Context*

This portion of the vignette described whether the situation concerned a primary care practice, often supplemented by the city or regional location of the practice. In some cases, the context was indicated by whom the patient was referred to and how long the patient was in treatment. We did not analyse these data in further detail.

### *Situation Sketch*

The researchers wanted to investigate whether patterns can be analysed in the descriptions of 'messy and confusing problems in the complex context of mental healthcare'. The Cynefin Framework van Snowden (Snowden & Boone, 2007) was used in this process. The Cynefin Framework is a sense-making model that fits the exploration of the data. It can help one to see things from new viewpoints, to assimilate complex concepts, and to address real-world problems and opportunities (*idem*). As a sense-making model it helps one characterize what kind of situation it is. The Cynefin Framework sorts situations into five contexts, defined by the nature of the relationship between cause and effect. These are: simple, complicated, complex and chaotic systems. In a *simple or obvious situation*, cause and effect relationships are predictable and repeatable. In a *complicated situation* there is a relation between cause and effect, but this relation is not self-evident. It requires more expertise to see the relations between cause and effect. When a situation is *complex*, cause and effect are only knowable in hindsight and the outcome is emergent and unpredictable. In chaotic situations the relationship between cause and effect is impossible to determine; there are no manageable patterns to define. In the middle of the Cynefin Framework there is also the unknown situation called *disorder*. In these situations it is not yet known if the situation is complicated and in need of more expertise or if the situation is, for instance, complex.

The review of the situation sketches was based on the following questions:

- *Are cause and effect both clear?* If the answer is yes, then we conclude it is a simple situation.
- *Is it possible to know what causes this situation and to predict the likely effect with more information?* If the answer is yes, then we conclude it is a complicated situation.
- *Are there many causes and effects interacting with each other that make the situation emergent?* If the answer is yes, then we conclude it is a complex situation.
- *Are there no manageable patterns to define?* If the answer is yes, then we conclude it is a chaotic situation.

While assessing the situation sketches, the researchers kept notes to stay aware of their own experiences and interpretations and to guard against potential 'inattentional blindness' (Simons & Chabris, 1999). This pitfall was offset as much as possible by re-reading the questions (as described above) after analysing each batch of five situation sketches, as well as rereading tips about the pitfalls of qualitative research.

## *Emotions*

The question related to the described emotions was 'which basic emotions (as described by Ekman) are mentioned in the vignettes?' The basic emotions described in the primary care psychologists' vignettes were coded as follows: joy, grief, anxiety, anger, surprise and aversion (Ekman, 1994). All other emotions that could not be coded as one of these six were assigned to two categories: the first group held emotions with a positive connotation ("I couldn't agree more") and the second held emotions with a negative connotation ("I felt I was flogging a dead horse"). Finally, there was a small rest category of 'other emotions', for example "I have mixed feelings about this". All instances of these emotions were tallied.

## *Parties Involved*

The question related to the parties involved was 'which and how many parties are mentioned?' All parties implicitly or explicitly involved in the situation were coded. An example of an 'implicit party' in a vignette is a general practitioner who plays a recognizable part in the situation but is not explicitly identified as the referring doctor. The parties and numbers of people involved were recorded for each vignette.



## *Norms and Values*

Our research on the norms and values was directed by the question ‘which norms and values are mentioned and how often?’ The vignette allowed the psychologists to record relevant norms and values. We define the concept of values as ‘opinions of what is desirable; motives and ideas that are regarded as worthy of pursuit’. We define the concept of norms as ‘concrete guidelines for action; the link between general values and concrete behaviour’. Most participants described one or more norms and values in each of their vignettes. However, the cases contained more norms and values than explicitly described by the participants. The researchers coded these and included them in the overall analysis.

## *Terminology Relating to Professional Conduct*

We looked at the vignettes and scanned them for terminology often used in descriptions of the professional conduct of primary care psychologists. This includes such terms as ‘making a diagnosis’ (diagnosis), ‘working in accordance with guidelines’ (guidelines), ‘methodology’ (method), ‘treatment’ (treatment) and words such as ‘disorder’, ‘depression’ and finally terminology indicating the ‘outcome of care’ (effect, result).

## **Research Findings**

### *Situation Sketch*

The participants described 113 vignettes of messy and confusing problems they experienced as complex. The researchers investigated whether this perceived complexity could be objectified. Here objectified means wanting to do justice to the object of study, to allow the object of study to speak for itself and not let it get distorted (Maso & Smaling, 1998). During the assessment the researchers took the texts of the situation sketch literally (semantic approach, Braun & Clarke). Thereupon the sketches were evaluated according to the Cynefin Framework as simple, complicated, complex or chaotic situations.

It was not easy for the researchers to ignore their own experiences, knowledge and judgement while reading and reviewing the sketches. Effectively they had to fight against the Dutch proverb *Een goed verstaander heeft maar een half woord nodig* (lit. trans. ‘An understanding person needs only half a word’ meaning: ‘A careful listener doesn’t have to ask twice’). It took a lot of effort and concentration to assess the literal

text, to remain aware of their own experience and keep feeling that this research work was valuable. Both researchers felt a strong palpable relationship between what they were reviewing and the idea they were involved in forging valuable progress. When they had to review literal wording and limit their personal interpretation to the minimum, then they felt less involved. When their commitment was reduced, the idea they were doing valuable research also diminished greatly.

Assessing the sketches triggered an association that defined the situations described as a static snapshot of a dynamic whole. During the analytical process the question of whether more information (measured as more words) would increase the likelihood that the situation could be assessed as complex or chaotic became relevant.

In assessing the four categories, the following became apparent in general. As expected, a *simple* vignette more or less described the cause and effect of the case. *Complicated* vignettes often contained multiple storylines (cause – effect) that all influenced one another but the effects were either described or predictable. *Complex* vignettes also contained several storylines but here the relation to the effects were hard to guess or were largely unknown. *Chaotic* vignettes described situations with unexpected twists and turns and the relationship with the effects was insufficiently clear.

Of the 113 vignettes (= 100%) 41 vignettes (36%) were rated simple with a recognizable relationship between cause and effect. For example:

*Because the practice has partnered with two health centres in a large city suburb, the number of referrals and thus registrations has increased rapidly in a short time, causing waiting times of six weeks or longer. The workload is increasing despite clients' complaining about the long wait. The 'background' is another factor in that the health insurers' contracts require that the waiting time be limited.*

39 vignettes (35%) were rated complicated. For example:

*Client (39) is living together, has an intellectual disability. She was neglected in her youth; parents divorced, father deceased and mother an alcoholic who does not want to see her daughter with her boyfriend. Client has siblings, but none of them wants to be in touch with her. Mother-in-law takes care of her. Treatment is focussed on achieving more independence. Although mother-in-law and therapist have doubts about the effect of treatment, the client is keen to continue.*

Of the 113 vignettes, 18 vignettes (16%) were rated complex and 15 (13%) chaotic. Example of a complex situation:

*Client (48) works at a municipal waste station. He was the only child of older parents. Both depressed. Mother admitted to psychiatric hospital, committed suicide. Father died young. Raised by grandparents. Did not have a normal childhood. He was taught that nothing he did ever mattered. Has been taking Seroxat (antidepressant) for years. Is thus scared he will lose his truck driving licence on re-examination. At an advanced age he married a woman from a very problematic family with lots of mental disability in the family. She is the only 'normal' one, and trained for a job in home care. This woman adopted a child with mental disability whose biological father has not recognized paternity. The son (16) has many behavioural problems and is in special education. Partners disagree strongly on how to deal with him. As the controversy the child knows well how to drive the parents apart. The reason for the request for help is that the woman thinks her husband should seek help, or she will put an end to their relationship. The client feels that nothing he does will ever be good enough for his wife and he suffers from her aloofness. ELP approach: clarify what is happening, consider what causes the disagreement, what happens then, how to deal with it, how partners interact with one another and how things could turn out.*

*Furthermore, normalizing the client's behaviour. The partner is invited to relationship therapy. Both have indicated what bothers them. They would like to see each other and learn how they could help one another. Wife keeps husband at an emotional distance, without indicating how he could/should get closer (sets unclear terms).*

*Meanwhile, the wife goes her own way. Client feels powerless, says he cannot get through his partner. "She's got a wall around herself and won't let anybody in"; "She's hard as nails, very black and white". She says that he must change, but doesn't say in what way or how. Client functions adequately and satisfactorily at work.*

Example of a chaotic situation:

*Woman (23), care worker; a first-line [primary care] psychological examination led to a referral to second-line [mental health care] on the basis of personality problems. Client was on sickness benefit. To bridge the long waiting time for second-line mental health care, the client was seen in our practice. Client appeared to have only basic health insurance which proved inadequate to cover the 'bridging time'. I soon learned that the client had a one-year employment contract which would expire in three months. The employer made implicitly it known that the contract would not be extended. The employer further informed me that while the client had been regarded as a good worker, her current status as 'unstable' entailed too much risk for the employer. During the waiting period, the client's problems stacked up*

*and she needed frequent support. Her [voluntary/family] carers were not prepared to provide this.*

We then examined if there was a difference between the number of words and the ratings of simple, complicated, complex and chaotic (see Table 1). The 113 vignettes contained a total of 17,674 words, an average of 156.4 words per vignette. The situation sketches rated simple had on average 107.21 words (total word count 4396, total vignettes 41). The situation sketches rated complicated had on average 167.85 words (total word count 6546, total vignettes 39). The situation sketches rated complex had on average 203.67 words (total word count 3666, total vignettes 18). The situation sketches rated chaotic had on average 204.4 words (total word count 3066, total vignettes 15). This means that simple situations averaged fewer words than complicated situations and in turn complicated situations averaged fewer words than complex situations. The average difference between complex and chaotic situations was minimal, 203.67 and 204.4, respectively.

**Table 1. Word Count.**

Category	Total vignettes	Total words per vignette	Average words per vignette
Simple	41	4,396	107.21
Complicated	39	6,546	167.85
Complex	18	3,666	203.67
Chaotic	15	3,066	204.40
Total	113	17,674	156.40

We conducted a General Linear Model Univariate analysis to examine if there was a difference in word count among the four assessment categories. The scores were derived independently of each other. Normal distribution was somewhat skewed due to the relatively limited number of participants. The categories in the population had equal variances. The ratio between the largest and smallest standard deviation is a factor of 3; the smallest standard deviation is 48.782 and the largest is 104.101. There is a strong effect on the average number of words between the four vignette categories ( $F(3,109) = 9.357, p < .001$ ). This effect is strong ( $\eta^2 = .205$ ).

A Bonferroni post hoc test was performed to determine which categories differed statistically on word count. This showed that simple differed from complex, chaotic and complicated. Simple averaged 60.63 fewer words than complicated ( $p = .006$ ), 96.45 fewer words than complex ( $p < .001$ ) and 97.18 fewer words than chaotic ( $p = .001$ ). The remaining three categories did not differ significantly from each other in terms of word count.

## *Emotions*

It soon became clear that the situations described in the vignettes are fraught with emotion. In total, 314 instances of emotion could be coded, on average 2,78 per vignette. Anger (in 83 of the 113 vignettes) was most frequent, followed by Joy (37 instances), Grief (36 instances), Anxiety (16 instances), Surprise (9 instances) and Aversion (2 instances). The emotions that could not be assigned easily to the basic emotions were coded as emotions with either a negative connotation or a positive connotation. Of these (123), 92 had a negative connotation and 31 a positive connotation. Finally, the rest category of emotions with a more or less neutral connotation was mentioned 8 times.

## *Parties Involved*

All vignettes involved a primary care psychologist (100%). A client was mentioned in 89.4% of the vignettes. The client's family was directly or indirectly involved in 46.9% of the situations. Their degree of involvement varied from being present at one or more of the sessions to being an important factor in the client's problems.

The primary care psychologists had most often contact with the GP (28 times). Specialists and welfare organizations were involved 24 times, followed by the occupational physician or client's employer (18 times). The health insurer was involved in 15 vignettes. Colleagues of the psychologists were involved 14 times. The government (varying from our legal system, social services and public authorities) was mentioned 11 times. In 6 vignettes other parties were mentioned such like regional cooperation's. On average the psychologists had to deal with 1,5 other persons (or organizations) at least.

## *Norms and Values*

The values described by the primary care psychologists were listed in a Top Ten. Several instances of values could be included. If a value (e.g. honesty) was mentioned four times in a vignette, it counted as one. The Top Ten values are: professionalism (35 instances), honesty (24), commitment (20), transparency (17), openness (16), responsibility (10), respect (9), sincerity (9), good care (8), justice (7) and respecting boundaries (7). In total 372 values were mentioned.

In 72 vignettes norms were described, in total 132 unique norms. 48 Norms could be placed in more than one category. The following categories were made: treatment by the primary care psychologist (40 norms), the professionalism of the primary care

psychologist (29), the therapeutic relationship (24), general decency (21), good care (if explicitly mentioned, 15), norms relating to other parties involved such as other care professionals (not immediate colleagues) and insurers (14), client behaviour (10), the primary care psychologist and society (10), collaboration within the practice and/or with colleagues (8), client interests (5) and, finally, professional interests (4).

### *Terminology Relating to Professional Conduct*

We investigated the extent to which concepts relating to professional conduct were described in the vignettes. This concerns words and phrases such as making the diagnosis (diagnosis), working in accordance with guidelines (guidelines), methodical (method), treatment (treatment) and words such as 'disorder' and 'depression' and finally terminology indicating the results of care (effect, result).

The word 'guidelines' was used in two of the 113 vignettes. The word 'effect' was used in five of the 113 vignettes and the word 'result' six times. Ten vignettes mentioned mental disorders. Symptoms of anxiety in the client were mentioned in 27 vignettes and words relating to depression (depressed feelings, symptoms and/or antidepressants) appeared in 34 vignettes. Personality problems were mentioned 12 times. 'Method' (covering method and methodical) appeared once. The word 'treatment' was present in 82 of the 113 vignettes.

### *Conclusions*

Our research question was 'What patterns can be analysed from vignettes describing messy and confusing problems in the complex context of mental healthcare?' The objective was to obtain a better understanding of the complex dynamic reality of primary care psychologists in mental healthcare. We tried to bridge the gap between objective, measurable reality as described and the complex and dynamic reality psychologists experience. The situation sketches were investigated with the aid of the Cynefin Framework because this tool facilitates making the complex rating (in addition to the simple, complicated and chaotic ratings). The Cynefin Framework also reflects the interest of researchers in complexity sciences.

Data analysis revealed the following patterns. All vignettes described situations experienced as complex. However, the researchers rated 36% of the vignettes as simple. This suggests that using a model fitting in complexity sciences (Cynafin Framework) does not guarantee showing the *experienced* complexity.

In addition, it could be established that the probability of a situation being assessed as complicated, complex or chaotic rose in proportion with more words being used to describe the situation. The vignettes were filled with emotion, with 'anger' appearing most often. The values 'professionalism' and 'honesty' and norms concerned treatment by the psychologist were mentioned most often. Besides the patient [client] and his/her family, the psychologists had to deal with on average 1.5 other persons (or organizations) at least. The vignettes hardly mentioned disease-oriented guidelines, but the words 'treatment', 'anxiety' and 'depression' were common.

Beforehand, the participants and researchers agreed on the following components of the vignettes: context, situation, emotions and norms and values. These components were first examined separately, obviously with the aim of analysing them together in the end. The researchers' experience in particular gave direction to this relationship. Accordingly, the researchers perceived the situation sketches as 'mere' snapshots of a broader and more dynamic entity, comparable to a scene from a film. They noticed that the descriptions of emotions and values also contained a lot of additional information that could explain the perceived complexity.

An example of a vignette experienced as complex but rated simple is as follows:

*Client (32), two children, from Curacao. Problems with autonomy. She is doing an internship at a nursery as part of a municipal rehabilitation project. The municipality has offered to reimburse consults not covered by her health insurance. Client calls off her appointment on the day itself: she has problems with her menstruation. I am allowed to send in the invoice [for her session], but I mustn't tell the municipality that that she did not turn up.*

We could answer yes to the question 'are both cause and effect clear?' Cause: client cancels appointment late. Effect: she must pay for the session. Cause: client is in a reintegration programme, has hardly any income so the municipality pays her bill. Result: Client asks the psychologist not to tell the municipality that she did not attend.

When we read the emotions associated with this situation sketch:

*Irritation that she has put me in a difficult position. I will not lie, but I also know that the consultation is too expensive for her to pay herself.*

And then, when we look at the values (and norms) described by this participant – honesty (you're honest) and goodwill (psychologist must show consideration for the patient) – the ethical dilemma for the psychologist becomes apparent: "I want to be honest and

I want to show leniency.” Dealing with ethical dilemmas demands multiple skills of the psychologist and when multiple stakeholders are involved, there is often talk of an incongruence of interests (Koocher & Keith–Spiegel, 2008).

All vignettes were fraught with emotions, which could contribute to the perceived complexity. In another vignette (also rated simple), for example, a participant describes the following:

*I feel indignation and anger: How dare she be so demanding. I also feel used and manipulated. I wonder how motivated she is to be treated and if I can still be her therapist. In any case, I no longer want to be her therapist.*

Besides the situation itself and the number of words (that can be) used to describe it, the associated emotions, potentially conflicting values and the involvement of several affected parties can explain why psychologists to consider messy and confusing problems in mental health care to be complex.

The high hard ground is concerned with ‘manageable problems’, where solutions are found ‘through the use of research–based theory and techniques’. Emotions, potentially conflicting norms and values, the involvement of multiple parties and especially the consistency of these cases all stand more in the background of the high hard ground. These constituents have been reduced from the disease–oriented guidelines. The personal story of the patient is often reduced to ‘required information’, symptoms consistent with a mental disorder. Meanwhile, the swampy lowlands (unruly day–to–day practice) are filled with emotions, norms and values. Treatment of a patient with for instance a depression, involves also dealing with the family of the patient or dealing with employers, working together with other healthcare professionals, struggling with dilemmas and having mixed feelings. These factors can explain why psychologists experience the swampy lowlands as complex.

## *Discussion*

In this research we studied the complexity psychologists experience while working in primary care. *Experienced complexity* is positioned in Schön’s swampy lowlands and Snowden’s Cynefin Framework was applied in order to grasp and ultimately distil some of its patterns. The aim was to obtain a better understanding of this complex dynamic reality. Although the vignettes themselves are all about treating patients, complexity is experienced most often in relation to the treatment context. This context includes the patient’s relatives, the collaborative partners such as GPs and occupational health



doctors, and health insurers, as well as fellow psychologists and psychiatrists. Playing a role in the background are social issues – such as the question of what is good care and who decides that – as well as potentially conflicting emotions, and norms and values. Covering both the theory and practice of mental illness treatment, this system is inextricably connected to the laws and regulations of the health care system, the emotions of the psychologists involved and the personal context of the patient.

This study deals with professional behaviour in a complex, dynamic system. It challenges us to develop another way of thinking.

*We need a kind of thinking that reconnects that which is disjointed and compartmentalized, that respects diversity as it recognizes unity, and that tries to discern interdependencies. We need a radical thinking (which gets to the root of problems), a multidimensional thinking, and an organizational or systemic thinking. (Morin, 2008, p. vii)*

Some examples. A complex dynamic system could be examined in terms of the *consistency* of its various elements and the *dynamics* of the system. But also in terms how to optimize the system's adaptive self-organizing ability. In the process, it would be good to apply not only traditional scientific theorems – such as the principle of universal determinism, the principle of reduction and principle of disjunction – but also the dialogic principle, the principle of organizational recursion and the holographic principle as used in complexity sciences (Morin, 2008, 2014).

Another challenge is to think in terms of causal feedback loops which can be either positive or negative. A positive loop will amplify an effect whereas a negative loop will inhibit or dampen an effect (Gershenson & Heylighen, 2005; Heylighen, 2001). The researchers' experience provides an example of both positive and negative loops in this study. The researchers felt attracted to the subject of 'swampy lowlands in the practice of psychology' (cause). That motivated them to undertake this study. Their commitment was reinforced by the emotions of the respondents, thus reinforcing the cause and resulting in a positive loop. However, while they were examining the data the researchers consciously adopted an objective stance, creating a distance (scientific method) that reduced their emotional involvement, which thus resulted in a negative loop or equilibrium. Their personal involvement returned when the data analysis was complete and distance was no longer necessary. Our next challenge is to explore what it takes to bring the psychologist's experience of complexity into a state of balance (equilibrium) without reducing or separating it into disparate elements.

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# Chapter 7

## Vignette Research on Messy and Confusing Problems in Primary Mental Healthcare

Smit D, Hill L, Walton I, Kendall S, de Lepeleire J. (2020)

European Forum for Primary Care: Position Paper for Primary Care Mental Health:

Time for change, now more than ever!

Primary Health Care Research & Development 21(e56): 1–8.

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## *Abstract*

There is a need for a paradigm shift across mental health in primary care to improve the lives of millions of Europeans. To contribute to this paradigm shift, the European Forum for Primary Care (EFPC–MH) working group for Mental Health, produced a Position Paper for Primary Care Mental Health outlining 14 themes that needed prioritizing. These themes were developed and discussed interactively during the EFPC conferences between 2012 and 2019. The Position Paper on Mental Health gives direction to the necessary improvements over the next ten years. The themes vary from preferable healthcare model to the social determinants highlighting issues such as inequalities. The Statement of Mental Health in Primary Care will be established in cooperation with fellow organizations.

## *Introduction*

The Organisation for Economic Co-operation and Development stated in 2017 that 'one in ten patients in OECD countries is unnecessarily harmed at the point of care' (OECD, 2017). Services and processes, the OECD claims, are either harmful or do not deliver enough benefits for patients, including those with mental health problems. In 2018, the OECD, more specifically, stated that better mental health care could improve the lives of millions of Europeans and contribute to stronger economic and employment conditions (OECD, 2018).

The European Forum for Primary Care argues, 'The majority of health complaints are dealt with through self-care and primary care, delivered in the local community. Addressing the needs of individuals in the context of their families and communities is one of the key features of primary care.' (EFPC, 2020). Primary care plays an important role in the prevention, detection, and overall improvement of mental health care.

The Mental Health working group of the European Forum for Primary Care (EFPC–MH) focuses on ways to improve healthcare policy. The key to this is to share experiences and identify current bottlenecks between national policies and local implementation. A key action of the EFPC–MH is sharing knowledge of what works from service users and clinicians by sharing evidence-based medicine and best practice to stimulate colleagues working in primary care to engage from across Europe to improve mental health care for their communities and themselves. The issues of the former EFPC Statement of Mental Health, from 2006, are partly achieved and needs to be updated.



In 2019, the EFPC–MH wrote a draft Position Statement for Primary Care Mental Health for discussion with the EFPC members and consulted fellow organizations like the European Community–based Mental Health Service Providers Network (EUCOMS), the European General Practice Research Network (EGPRN), and Mental Health Europe (MHE). In 2020, the final EFPC Statement is now published. This article gives an oversight of the development of the statement and its issues.

### *Research design*

In 2012, the working group EFPC–MH started by listening to what healthcare professionals, social and welfare professionals, and service users indicated about actual day–to–day problems in giving and receiving mental health care in a primary care setting. Subjects such as problematic access to secondary care mental health, lack of research and education in primary care, and social determinants such as poverty and inequality were discussed and were connected to (poor) mental health and its management.

We gained data by semi–structured EFPC workshops annually, allowing us to consult with international attendees, practitioners, and patients, from around 46 countries worldwide. In addition, we gratefully made use of the knowledge obtained from experts during the conferences. We also made use of our sources in between conferences. We also did frequent literature searches to be able to link information to scientific research and/or to available policy information.

We used social research as outlined by Greene (2007) where–upon we had four domains. The first domain addressed philosophical assumptions and different stances. The conferences where we explored this, were attended by students, researchers, professionals, and service users. There were professional views and lived experiences that shaped the work and helped challenge the assumptions. This enabled us to investigate further what was known from those who were best placed and provide a context within Primary Care Mental Health. Within the second domain, we recognized the interconnectedness of what was produced and how this started to give consistent messages. We then took into consideration professional guidelines for practice and by listening to service users we began to understand the need for a paradigm shift on the way that Primary Care Mental Health is understood and delivered. This leads us to the final domain on producing the EFPC position statement, which is our sociopolitical statement, enabling us to have discussions across providers and prioritize which issues and solutions do the most justice to what the parties have shared with us.

Although the whole project was yearly well thought out, at many times, we were surprised by unexpected information, conflicting solutions and judgments, and workshops that had an unexpected dynamic that caused a shift in subject. In these cases, we used an iterative way to interpret what was said and identify the semantics by reflecting on what was captured on worksheets and examining the meaning to gain the perspectives of those attending conferences and workshops in Primary Care Mental Health (Sarantakos, 2005).

### *The development of the themes*

2012 Gothenburg – The authors, four Primary Care Mental Health practitioners and enthusiasts, from Belgium, the Netherlands, and the UK, met whilst each delivering separate presentations at the EFPC conference in Gothenburg. Working with the attendees of our workshops, we were able to issue our first, very brief consensus statement.

*“Across Europe, there is a problem with the organisation of mental health care due to siloes, a lack of integration, tribalism, different perspectives between medical, social, and psychological care.”*

2013 Istanbul – It was found that participants believed that mental health was generally detected well in primary care, however, there was little focus on prevention. There were gaps between primary and secondary care with little integration between health and social care and once in secondary care, the patient’s psychiatric needs were met, but not their social and physical needs.

2014 Barcelona – Focused on a common understanding of what we were talking about and look for common understanding and values. Themes produced included a need for educational programs, a consensus on ethical values, and how we measure quality and outcomes.

2015 Lille (Primary Care Mental Health Conference) – Recovery was the theme and it was found that it needed to be explored more from a survivor and a professional perspective. This needed to include preparation for life with social skills built-in. Good mental health should be explored and taught at a young age to develop resilience and problem-solving skills.

2015 Amsterdam – The need and means for helping, supporting, and managing mental ill-health and trauma of refugee and asylum seekers were explored with strategies for anti-discriminatory practice put forward.

2016 Riga – Understanding and explaining complexity in Primary Care was key and this workshop allowed the exploration and a model for management in primary care.

2017 Porto – Understanding and discovering major alignment with policy statements from the World Health Organization (Saxena *et al.*, 2006; WHO, 2015) and the United Nations (Pūras, 2017) and defining the major messages concerning the themes produced in the burgeoning position statement.

2018 Heraklion – Refining and consulting on the individual areas of the document to develop priorities, consensus, and meaning from what had been produced so far.

2019 Nanterre – Presentation of draft finished document for comment, amendment and to share the results of the literature review and by informing the themes produced.

The EFPC Statement of Mental Health initially included 13 themes, first looking at the problems needing to be addressed as brought up by participants in our workshops and then potential solutions. The headings are access, co-creation, complexity, education, inequality, information technology, leadership, a model of care, prevention, research, self-care, spirituality, and workforce development. After presenting these issues in an EFPC webinar in February 2020 and a consultation with EUCOMs on the themes from the position statement, it was decided to add another important heading, Diagnosis. Although it had not come up as a major topic in our workshops, we realized it was important for better joint working with social and secondary care as it helps us to understand why, particularly in Primary Care, the individual is more important than the disease.

## **The themes**

### *Access*

Early intervention and support are evidenced to alleviate distress and improve outcomes (Bird *et al.*, 2010; McGorry and Mei, 2018; Read *et al.*, 2018). However, the workshops showed that early intervention is not available in all countries. It was reported that people met barriers and received little or no help until they reach the threshold to meet the criteria to enter services. However, not all receive access to specialized treatment due to their diagnosis or having a comorbidity such as addictions or physical health problems. Access barriers leave people suffering on waiting lists, often unrecognized, misdiagnosed, misunderstood, or ending up in different parts of the system, notably the criminal justice system. Countries with a health insurance funding system reported that treatment was only available for those with symptoms that fitted specific 'diseases'. Countries without

health insurance reported a ‘lottery’ of health care with no consistency of services nor allocation of resources. All countries reported that funding for mental health services is not equal to physical health.

To get a better and fair access to mental health care in a primary care setting, there should be no artificial limits if you require care. Access needs to be at the right time, in the right place, by the right person with the right skills. Primary care can enable swift access at a low level and recognition stage (Dowrick *et al.*, 2016). Collaboration ensures that the patient can get the support they need when they need it, including housing, benefits, work, family, social support, therapy, and specialized mental and physical health services. Primary care offers a continuation of support that matches need, freeing up demand for specialist services. Specialist services need to be working collaboratively with communities that involve patient and caregiver voices, primary care, social care, and the voluntary sector in an integrated system to support the patient on their path to recovery (Woltmann *et al.*, 2012).

### *Co-creation*

Throughout the workshops, it was voiced that there could be no improvements and decisions made without the patient at the heart of all that was done. Concern was expressed that co-creation is frequently discussed and is represented in international policy documents and is rightly best practice, but, is seldom delivered upon. A systematic review of the literature (Manikam *et al.*, 2017) evidences this view demonstrating the growth of published material from 6 to 150 papers from 2006. However, these are across all of health showing co-creation remains an under-resourced and under-invested area of Primary Care Mental Health. Evidence shows that language and access to some cultural communities are barriers in meeting their mental health needs and co-production could increase participation rates to improve the quality of services (Lloyd *et al.*, 2008; Minogue and Girdlestone, 2010).

To do justice to co-creation patients and caregivers need to be at the heart of all we do, and their voices must be heard within any system change. Integrated pathways of care will work when patient and caregiver experiences are shared, and their world view is understood. The World Health Organization (Murray *et al.*, 1996) emphasizes the need for people-centered health services, which sees people as participants as well as beneficiaries of health care services. Primary Care Mental Health services of the future need to be integrated, responsive, and compassionate in their response. Patients need the education and support they need to make decisions and participate in their care. (World Health Organisation, 2015). This will ensure that services are tailored to

meet the breadth and depth of need from local community sources. Investment and mainstreaming of patient-led research and evaluation will benefit services, communities, and individuals alike.

### *Complexity in primary care*

Mental health is individual with complex biological, social, spiritual, cultural, medical, psychological, existential, and economic factors interconnecting. Clinical guidelines and evidence-based medicine focus on single issues and the best treatment for a sample population that tends to exclude people by age, culture, and gender (Smit and Derksen, 2017). We need to acknowledge the individual, consider comorbidity, and the interconnectedness of all factors. It is time to change systems of care (Sturmberg *et al.*, 2014).

Building teams around primary care to link patients into the community and local mental health services is a good way of ensuring that every individual can be supported to meet their complex needs (Thota *et al.*, 2012). The EFPC underlines that primary care practitioners are experts in complexity, acknowledging the individual, their surroundings, and the interactions between physical and mental health and the need to look after both (Kringos *et al.*, 2010). They are rooted in their communities and in a good position to know about both the problems and the assets within the areas they work in.

### *Diagnosis of mental health disorders*

The use of psychiatric diagnosis in primary care is problematic (Vanheule *et al.*, 2019). A psychiatric diagnosis misses the individual context of the patient, which is needed to weigh up the symptoms and to answer the request for help (Van Os, 2014). The complaints of the patient are often compounded. Moreover, there is a huge amount of overlap in symptoms resulting in difficulties with classification. A diagnosis does not tell us much about what kind of treatment the patient needs (Allsopp *et al.*, 2019). The professional guidelines, linked to the DSM-5 diagnoses, tend to medicalize mental problems, whereas in primary care contextualized mental health problems are presented and managed.

Instead of focusing on the diagnosis regarding mental health problems, the focus should be much more pragmatic. This pragmatic approach allows recognition of individual experience and gives a better understanding of the distress of the patient (Allsopp *et al.*, 2019). This could be as easy as asking four questions: what happened to you? What is your vulnerability and what is your strength? Where do you want to go? What do you

need? (Van Os, 2014; Delespaul et al., 2017). From an integrated care perspective, we advocate for a centralized role for the patient based on their individual needs supported by a whole system approach including local caregivers. Primary Care Mental Health problems should be seen in a context where treatment will stimulate normalization and self-care in harmony with the patient.

## *Education*

The views were that there is a lack of awareness and skills in communicating and managing well-being and mental health across the whole population, resulting in fear and stigma. The literature supports this view of stigma not just being at a population level but also across professions (Schulze, 2007), education (Martin, 2010), disciplines including physicians (Wallace *et al.*, 2009), communities, and whole countries (Saraceno *et al.*, 2007).

A workforce, fit for the future, requires education that is fit for purpose at all levels. There is a need for education that enables awareness of mental health and well-being from an early age to enable prevention, early detection and to address stigma, the entire population requires a level of knowledge. Research shows that contact combined with education seems to be the most promising avenue (Rüsch *et al.*, 2005; Thompson *et al.*, 2010). Professionally, mental health needs to be embedded across the curriculum of all disciplines starting at an undergraduate level and continuing through post-graduate training and continuing professional development. Co-production and a wider knowledge base that builds on the needs and experience of service users for their recovery journeys (Leamy, 2011; Stuart *et al.*, 2017) is key, as is reflecting people's cultural and spiritual needs.

## *Inequality*

Mental health is not discriminatory. We know that certain areas are at higher risk of mental health problems because of greater exposure and vulnerability to unfavorable social, economic, and environmental circumstances (Barnett, 2012; Wilkinson and Pickett, 2017; Ribeiro *et al.*, 2017). Nurture, love, support, and freedom to grow are necessary to develop into a healthy adult, but those born in poorer families and poorer areas have an increased risk of mental health problems in later life (Vannieuwenborg *et al.*, 2015; Tong *et al.*, 2018). There are fewer mental health problems in societies where the population feels they have control over their lives and are involved in decision-making. The poor have less choice and societies are happiest where inequalities are lowest. Poverty divides

society and is a major factor for mental illness, the dispossessed lose hope and feel left behind whilst the rich fear losing the security of their wealth.

Inequalities caused by adverse life events, racism, and other forms of discrimination, abuse, violence, neglect, immigration, refugees, asylum seekers, illness, bereavement, relationship breakdown, contact with the criminal justice system and institutional care are all related to an increased risk of mental health problems. There is enough evidence that we should strive for fewer income differences to improve the health and well-being of populations (Pickett and Wilkinson, 2015; Barnett *et al.*, 2012). We will not reduce the stigma associated with mental illness, unless we recognize this and focus on the causes and reduction of their impact, instead of blaming it on inherent weakness in the individual (Clement *et al.*, 2015).

### *Information technology*

Concern was shared regards the growing shortage of General Practitioners all over Europe. It was voiced that health care systems alone will not be enough to meet the growing need for treatment of mental health problems (Bodenheimer and Smith, 2013). Social media can isolate and be the cause of deterioration of mental health through cyberbullying and social isolation, but it can also be used to benefit mental health by providing education and therapy programs. There is a gap in our knowledge as to the impact of these programs, this gap should be narrowed down.

Information technology has the potential to help those with mental health problems, alongside those who support them. We must make this information technology accessible for everyone, not only for people who can afford it (Allen and Christie, 2016). E-health web-based health interventions have been shown to increase access to care (Hilty *et al.*, 2013). There is evidence of websites, apps and other technologies, which used wisely can be of benefit, particularly to those unable or unwilling to access health and social care services. Guided Internet interventions seem to be cost-effective (Donker *et al.*, 2015).

Information technology cannot replace the human touch; however, it can be used to the benefit of many, either with or without therapist and clinician support. Further research and investment are needed in this area.

### *Leadership*

To create change, there needs to be governmental, clinical, community, and patient ownership. Within these areas champions for mental health are needed. Like all other

conditions presenting in primary care, the approach should be biopsychosocial and existential. 'There needs to be an integrated approach which is case managed with a recognition that it corresponds with complexity sciences which have cohesion and dynamics in their focus' (Smit and Derksen, 2015).

The process of change is one that needs guidance and understanding, which requires leadership at all levels. We know 'one size does not fit all', so it is important to recognize the uniqueness of each environment and tailor services to meet population needs with leaders to inspire that change. These leaders need to be visible throughout society in schools, faith centers, education, and medicine. Their role is simple to inspire others to create change and develop ownership. Therefore, to enable the rhetoric of national and international statements advocating a change in mental health to become a reality, we need transformational leadership to inspire the change (Hallinger, 2003; Day and Harrison, 2007; Plesk and Greenhalgh, 2001; Plesk and Wilson, 2001; Sturmberg and Martin, 2012; Sturmberg et al., 2012).

### *Model of care*

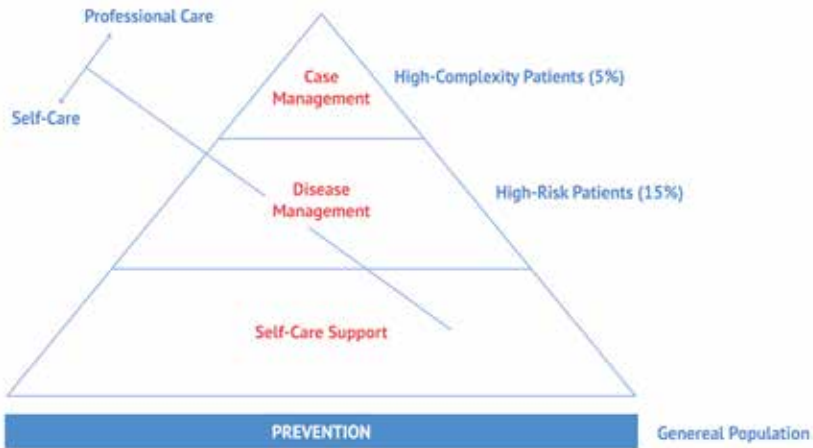
Family doctors, from all countries, support people across society and at all stages of their life course. Good primary care provides compassion and cares for the individual, from conception to a good death. There needs to be the recognition that every child, man, or woman has their own unique needs when experiencing mental ill-health. There also needs to be a clear recognition of the families and caregivers, who also have distinct needs that are often not understood in the school, community, and workplace environments.

Therefore, the EFPC states that integrated working is a priority across community, health, and social care, with best practice examples needing to be understood and shared. Integrated care needs to be at a local level, with skill mix and holistic representation linked to primary care. For more complex needs a dedicated team around the person, offering available support twenty-four hours a day, was identified as key. Mental health needs a clear equitable model of care, which includes investment in prevention, early intervention, access, treatment, and recovery. There is evidence from the USA, Belgium, and the UK that approximately 50% of healthcare costs come from 5% of the population. These high costs, high need patients are often complex and involve multiple agencies (Blumenthal *et al.*, 2016; Rosen, 2018). Adopting a risk stratification model (Figure 1) as a framework to develop a fresh approach for mental health will ensure that investment and integration are key pillars of development. It will also address those more complex patients presenting with comorbidities (Thornicroft *et al.*, 2017).



Whilst increasing expenditure on mental health is important it is not the sole driver of change. Improved care and outcomes are equally as important. Reducing inequities in geographic coverage and meeting unmet need means using Primary Care as the first point of support and entry prevents the spiraling of distress and enables the reduction in avoidable hospitalizations. Kaiser Permanente, an American Health Organization, has developed a risk stratification model (Jadad *et al.*, 2010) which has been also used in the UK to categorize levels of care.

**Figure 1. Proposed model of care for mental health based on Kaiser Permanente risk stratification pyramid.**



‘Case management’ ensures coordination for individuals with complex needs requiring integrated high health and social care support. ‘Care management’, at the next level, provides for high risk individuals using peer support and education. ‘Supported self-management’ is the level of care for individuals with good control of their mental health in recovery needing only routine medical review. The ‘risk stratification’ allows a framework for both health promotions in the community and for identifying clients at risk.

## *Prevention*

The European Forum for Primary Care recognizes that the mental health issues presented in primary care are often preventable and can be caused by external and environmental factors (Patel *et al.*, 2010; Hughes *et al.*, 2017). These factors are diverse and include global issues such as war (Lindert *et al.*, 2016; Miller and Rasmussen, 2017), disease (Scott *et al.*, 2009), inequalities (Wilkinson and Pickett, 2017), maltreatment in childhood (Angelakis *et al.*, 2019; Norman *et al.*, 2012), poverty (Patel *et al.*, 2010), and debt (Sweet *et al.*, 2013). Within affluent societies, despite policies and investment, mental health needs are not a priority, are not reducing and in some countries are in-

creasing (Jorm, 2014). Current predictions indicate that by 2030, depression will be the leading cause of disease burden globally (World Health Organisation, 2011) The impact is far-reaching, going beyond a global economic issue, to one which, on a personal, family and community level, impact on people's spiritual, social, economic, physical, and psychological well-being.

To enable mental and physical health to be of equal status and ensure parity of esteem requires research, evidence, and investment (Sabbe, 2013). The use of education, including mental health promotion, would enable a population approach to manage this ever-increasing problem. Supporting this is the move toward social prescribing in primary care and the use of the community and third sector (Maughan et al., 2016). Therefore, a fundamental paradigm shift toward prevention (Jorm, 2014; Keet et al., 2019) and community-based services including primary care is required (Knapp et al., 2011). This needs to be holistic and compassionate requiring both government strategic support and investment.

## *Research*

Due to a paucity of accurate data and data analysis regarding Primary Care Mental Health, there is a lack of knowledge and extensive rhetoric at national and international levels that is not well informed. In line with the paradigmatic shift toward an understanding of a praxis of health care that takes account of its complexities, we also need new methods for research (Sturmborg, 2019). Accurate data will allow the rebalance between self-care and professional care, addressing this data gap. It will inform the redrafting of strategy and policy in Primary Care Mental Health and guide a whole system review for a system that works. It is imperative that research is independent and informed by the patient's voice, carers and professionals working in communities. Technological solutions also need to be researched as to what works and why, only then can complexity be properly addressed.

## *Self-care*

Psychological, social and medical care are available for only short periods, compared to the amount of time that people need to self-care. People are social creatures, for whom altruism, doing things for others is well-evidenced for creating well-being and happiness (Post, 2005; Aknin et al., 2015). Increasingly, particularly in affluent societies loneliness and isolation, known to be detrimental to health (Victor and Yang, 2012; Beutel et al., 2017; Stickley and Koyanagi, 2018; Jessen et al., 2018) and chasing money,

rather than happiness, is becoming the norm. Data shows that obesity (Davillas *et al.*, 2016), smoking (Steinberg *et al.*, 2015) and taking drugs (Morley *et al.*, 2015) and drinking alcohol (Mäkelä *et al.*, 2015) are more common in those with mental health issues, as is lower life expectancy.

Self-care should however not be an excuse for no care. Primary care is in an excellent position to work with patients to create individual lifestyle choices that benefit themselves and the wider community. This will also address issues, such as the negative symptoms normally associated with mental illness, stigma and isolation as well as promoting well-being across the life course. Physical health and mental health are interlinked (Ohrnberger *et al.*, 2017) and health promotion is required at an entire population level. The cornerstone of recovery is hope (Hobbs and Baker, 2012) and underpinning all self-care is that you can recover to be the best you can be.

### *Spirituality*

We recognize that there are often cultural and spiritual interpretations of mental ill-health, such as black magic, Jinn or juju. The workforce, and society struggle to understand these non-western concepts. They can result not only in isolation and fear for the patient but also for the wider community.

Working with communities to understand their worldview is a vital part of primary care, who are placed in the heart of the community. Recruiting people from different backgrounds with different knowledge bases and adopting a policy of community engagement will enable understanding. Harnessing the knowledge of existing staff and the wider community will also help. Within primary care, there is a growing evidence for the use of Chaplains for Well-being supporting issues such as bereavement and loss (Mowat *et al.*, 2012; Puchalski *et al.*, 2014; Balboni *et al.*, 2014; Kevern and Hill, 2015; Mc Sherry *et al.*, 2016).

### *Workforce development*

Within the EFPCMH workshops, patients stated that they feel they are not being listened to. General practitioners and nurses expressed that there is little time to listen and they had not been adequately trained. Primary care staff felt overwhelmed with the volume of mental health and felt that they were left to manage Mental Health in Primary Care needs to be delivered by a workforce with the skills to assess, manage and treat mental health. This involves developing the interpersonal skills to enable recovery,

offering hope and trust. The person needs to be available at the right time, in the right place, offering the right care in the right manner.

Suggestions for new roles in primary care that have been trialed successfully include the role of a social navigator, to navigate the patient through the complexities of the health and social care system (Dohan and Schrag, 2005; Natale–Pereira et al., 2011) and case managers, potentially a generalist role, that proactively supports and coordinates people with mental health problems at a primary care level (Bodenheimer et al., 2002; Wallace et al., 2015) and Chaplains for Well–being (Kevern and Hill, 2015; Mc Sherry et al., 2016).

### *Down to work!*

To improve mental health care in a primary care setting is an ongoing business. Mental health services in primary care need to develop in a direction whereby they have the capacity and the ability to reach all in our society, particularly those who have the greatest need. The position statement describes the approach that is needed, focussing on the individual, the communities we live in, and services that are integrated. Primary care practitioners with the correct support and training are well–positioned to be central and to coordinate this approach. Research in Primary Care Mental Health remains in its infancy, but if we are to bring mental health services into the 21st century, there is an urgency to invest the means of evaluating the outcomes and ensuring quality as services evolve.

The Norwegian Council for Research (NCR) has funded a research network led by the Centre for Care Research (CCR) in 2018. The Research Unit for General Practice at the University of Bergen, Norway and the European Forum for Primary Care are also partners in this European PRImary care MultiprOfessional Research network (PRIMORE). PRIMORE gave the EFPC–MH working group the opportunity to investigate the relations between mental health care and the connected subjects of education, poverty, and inequality.

Today, the COVID–19 pandemic shows us – again – the urgent need to invest in mental health care. In the policy brief on COVID–19 and mental health issued by the United Nations, Dr Tedros Adhanom Ghebreyesus, Director General of the World Health Organization, noted he is extremely concerned about the impact of the pandemic on people's mental health (WHO, 2020) not only the patients recovered from the COVID–19 virus, but also family members, frontline health care workers, the elderly due the stay–at–home measures, women, particularly those who are juggling home schooling, working from home and household tasks, and all those who lost their job and/or income. Again, during

this corona crisis, most attention went to physical health care, even though mental health should – in all circumstances, be at the core of our humanity, because – as the UN Secretary-General, Antonio Guterres – states ‘it enables us to lead rich and fulfilling lives and to participate in our communities,’ (UN, 2020).

The EFPC underlines again and strongly the statement of Dévora Kestel, Director of the Department of Mental Health and Substance Use at WHO. ‘The scaling-up and reorganization of mental health services that is now needed on a global scale is an opportunity to build a mental health system that is fit for the future.’ (WHO, 2020).

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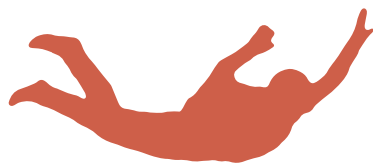


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# Chapter 8

## De complexiteit van christelijke geestelijke gezondheidszorg

Smit D. De complexiteit van christelijke geestelijke gezondheidszorg.

Psyche & Geloof. 2016(4):206–16.



## *Samenvatting*

Wat is ervoor nodig om als christelijke zorgorganisatie binnen de geestelijke gezondheidszorg aan christelijke waarden een volwaardige plek geven in de uitvoering en de organisatie van de zorg? Om deze vraag te beantwoorden is gekeken wat de formele omschrijving van geestelijke gezondheidszorg is en of de christelijke visie op zorg, zoals de landelijke GGZ-organisatie Eleos die hanteert, aansluit bij deze omschrijving. Vervolgens is gekeken of de formele omschrijving van de geestelijke gezondheidszorg recht doet aan de complexiteit van de dagelijkse praktijk. De GGZ kan omschreven worden als een complex (adaptief) systeem, waarbinnen een veelvoud aan factoren op onvoorspelbare wijze op elkaar ingrijpen. Het organiseren van christelijke geestelijke gezondheidszorg vraagt daarom een ander organisatiemodel namelijk die van de lerende organisatie. Voor de zorgprofessional, werkzaam bij een zorgorganisatie voor christelijke GGZ, betekent de herstelgeoriënteerde zorg vanuit een christelijke visie vooral dat er een groot beroep wordt gedaan op persoonlijk meesterschap, een van de disciplines van de lerende organisatie. Nagegaan wordt onder welke condities dit meesterschap kan gedijen.

**Trefwoorden:** Christelijke visie, GGZ, lerende organisatie, complexiteit.

## *Geneeskundige Geestelijke Gezondheidszorg*

Het Zorginstituut Nederland omschrijft de geneeskundige geestelijke gezondheidszorg als volgt:

*Geneeskundige GGZ binnen de Zvw voor verzekerden van 18 jaar en ouder, omvat zorg, die de betrokken beroepsgroep tot het aanvaarde arsenaal van medische onderzoeks- en behandelingsmogelijkheden rekent en die gericht is op herstel of voorkoming van verergering van een psychische stoornis. (Zorginstituut Nederland, 2016).*

In deze omschrijving wordt gesproken van een 'gerichtheid' op herstel. Deze gerichtheid legt de nadruk op 'in een bepaalde richting plaatsen' (Van Dale, 2015) van de zorg. De Zorgverzekeringswet (Zvw) geeft vervolgens aan op welke medisch noodzakelijke zorg iemand recht heeft. Geneeskundige GGZ is zorg gericht op de behandeling van een psychische stoornis (Zorginstituut Nederland, 2016). Er is bewust gekozen voor het begrip psychische stoornis omdat dit beter aansluit bij de terminologie van de internationaal gebruikte DSM-classificatie (Diagnostic and Statistical Manual of Mental Disorders, APA, 2000). De formele omschrijving van geneeskundige geestelijke gezondheidszorg past daarmee binnen de uitgangspunten van het biomedisch model (Stein, 2010).



## *Christelijke Geneeskundige Geestelijke Gezondheidszorg*

Binnen het biomedisch model lijkt er weinig ruimte zijn voor zingeving en/of religiositeit. Een christelijke visie op zorg, waarbij zorg en religiositeit worden gecombineerd, is dan ook niet eenvoudig. Een uniforme en door een ieder gelijk geïnterpreteerde christelijke visie ontbreekt, en ook de relatie met God kent vele vormen. Op hoofdlijnen zou een christelijke visie omschreven kunnen worden als een levensbeschouwing die door het geloof verbonden is aan Jezus Christus en berust op twee fundamenteën: de bijzondere openbaring (Bijbel) en de algemene openbaring (de door God geschapen orde). Zorg vanuit een christelijke visie betekent bewogenheid met mensen die lijden vanuit Gods liefde voor mensen. Vanuit Zijn barmhartigheid wordt omgezien naar anderen, in dit geval mensen met psychische klachten. De verantwoordelijkheid die vanuit de christelijke visie wordt gevoeld, wordt gedragen in afhankelijkheid van God. Er wordt gestreefd naar verbondenheid, elkaar tot een hand en een voet willen zijn. De christelijke visie wil hoop bieden en een voedende relatie met God stimuleren. Daarmee kent deze visie een meer transcendent zingevingskader. Dit verschilt van de seculiere opvatting met een meer immanent zingevingskader, waarbij zingeving meer samenvalt met een individualistische visie.

Eleos, een zorginstelling voor christelijke GGZ, heeft gekozen voor een *herstelgeoriënteerde* zorg vanuit een christelijke visie (Eleos, n.d.). De nadruk ligt op 'oriëntatie', hetgeen betekent 'nagaan waar je je bevindt, je van de verhoudingen op de hoogte stellen' (Van Dale, 2015). Deze visie sluit aan bij de herstelbenadering van Whitley en Drake, met name vanwege de expliciete plek die zij geven aan existentieel herstel (Whitley & Drake, 2010, Drake & Whitley, 2014). Whitley en Drake maken onderscheid in de volgende vijf dimensies van herstellen: klinisch, existentieel, functioneel, lichamelijk en sociaal herstel. Elke dimensie omvat vervolgens een aantal items die passen bij deze hersteldimensie, maar niet exclusief voor deze dimensie hoeven te zijn. Deze zijn bij Eleos in onderstaand herstelmodel vorm gegeven.



Patiënt en behandelaar kiezen samen op welke hersteldimensies de behandeling gericht dient te zijn en welke behandelmethode hier het beste bij past. Zo kan een patiënt bijvoorbeeld behandeld worden middels psychotherapie of farmacotherapie bij het verminderen van de symptomen, middels e-health bij het verbeteren van de balans tussen rust en activiteit of het verbeteren van klacht-gerelateerde geloofsvragen en kunnen ervaringsdeskundigen worden ingezet bij het vergroten van het gevoel van hoop. De vijf hersteldimensies maken tevens duidelijk dat herstel voor een patiënt veel meer is dan sec het herstel van de psychische stoornis zoals weergegeven in de formele beschrijving van geneeskundige GGZ.

### *Christelijke ggz in de praktijk*

In de huidige gesecculariseerde samenleving is religie geen eenduidig overkoepelend zingevings-systeem meer, maar een subsysteem naast andere subsystemen (Schepens, 1997). Religiositeit lijkt tot het privédoein te zijn verklaard, los van de organisatiestructuur (idem). Dit heeft de schijn dat je een christelijke visie niet hoeft te *organiseren*, maar dat het aannemen van christelijke medewerkers wellicht voldoende is. De christelijke visie beperkt zich dan tot het aannamebeleid en een begrensd aantal kerkelijk-godsdienstige rituelen die uitgevoerd *mogen* worden.

Zorgorganisaties hebben, naast het bieden van zorg, met veel meer te maken dan sec het organiseren van 'medische onderzoeks- en behandelmogelijkheden die gericht is op herstel of voorkoming van verergering van een psychische stoornis'. Hier

volgen een aantal voorbeelden, te beginnen bij de groeiende weerstand tegen de DSM-classificatie (American Psychiatric Association, 2013), het medicaliseringsvraagstuk. Allen Frances, lid van de DSM-III task force en voorzitter van de DSM-IV task force maakt zich zorgen over de medicalisering van psychische klachten (Frances, 2013, 2012). Hij wil de normaliteit beschermen tegen medicalisering en de psychiatrie tegen overexpansie. Wakefield voegt daar zijn kritiek aan toe dat met de DSM-5 meer vals positieve diagnoses kunnen worden gesteld (Wakefield, 2015). Ook in Nederland vragen diverse vooraanstaande zorgprofessionals, zoals psychiater Van Os, aandacht voor de gevolgen van de DSM-classificatie. In het pamflet *De nieuwe GGZ* stellen zij dat 'de patiënt gereduceerd wordt tot zijn of haar symptomen en geen regie en eigen verantwoordelijkheid toebedeeld krijgt' (Waarom de nieuwe GGZ, n.d.). Deze visie op zorg wordt breed gedeeld in Nederland, getuige onder andere de 30.000 handtekeningen voor het burgerinitiatief *Het roer moet om* (Het roer moet om, n.d.). Het sluit ook aan bij de visie van het Landelijk Platform GGZ. Zij vinden het wenselijk en noodzakelijk om meer de nadruk te leggen op zelfmanagement, eigen regie, herstel en herstel-ondersteunende zorg. Volgens het Landelijk Platform GGZ is eigen regie 'een duurzaam en houdbaar stelsel voor zorg en maatschappelijke ondersteuning op alle levens-gebieden. Daarbij wordt uitgegaan van de behoeften, eigen regie en eigen kracht van mensen' (Het Landelijk Platform GGZ, 2012). Een dergelijk immanent zingevingskader, met de nadruk op eigen regie, wordt ook vanuit de overheid gestimuleerd (Basis GGZ en gespecialiseerde GGZ, n.d). Op de website van de Rijkoverheidsdienst wordt bij de beschrijving van de generalistische basis-GGZ vermeld: 'Binnen de Basis GGZ is er ruimte om zelf grip te houden op uw leven. Of op de benodigde behandeling en ondersteuning. U kunt het beste met uw zorgaanbieder bespreken hoe hier invulling aan te geven' (idem).

Maar er is meer. De GGZ heeft te maken met een lange lijst met ontwikkelingen. Ten eerste de voortdurende stroom aan 'verbeteringen of hervormingen' binnen de GGZ. De invoering van de generalistische basis- en gespecialiseerde GGZ, de transitie en transformatie van de jeugdzorg, de ambulantisering, de herinvoering van omzetplafonds en de daarmee gepaard gaande wachtlijsten, de invoering van e-health producten en de nadruk op *shared decision making*, eigen regie en zelfredzaamheid van de patiënt. Daarnaast liggen er een behoorlijk aantal veranderingen in het verschiet, onder andere de doorontwikkeling van de DBC-structuur in 2019.

Een tweede ontwikkeling is de economisering van de zorg, waarbij het denken in producten, prijs, promotie en plaats steeds dominanter is geworden. De generalistische basis-GGZ bestaat uit een aantal zorgproducten en de gespecialiseerde GGZ werkt naar voorkeur van de zorgverzekeraars op basis van vastgestelde *zorgprogramma's*, die zowel inhoudelijk als financieel vooraf zijn doorgerekend. Daarnaast zijn er GGZ-instellingen

die marketingposters in de metro hangen (*Kamerstukken II 2012/13, 2013D03458*), is er een voortdurende zoektocht naar innovatieve zorgproducten en wordt de nadruk gelegd op het centraal stellen van de klant. Ook de kosten van de zorg is een dominant en terugkerend thema binnen de zorg. In 2011 waren er al grote zorgen over de vergrijzing en de stijgende zorgkosten. Het Centraal Planbureau (CPB) had berekend dat de zorguitgaven sinds 1972 onafgebroken waren gestegen (van 8 procent naar 13 procent van het bruto nationaal product). De verwachting was dat het percentage in 2040 zou stijgen naar ongeveer 19 tot 31 procent (Van der Horst, Van Erp & De Jong, 2011). In 2016 kon het Centraal Bureau voor de Statistiek (CBS) echter vaststellen dat de zorguitgaven weliswaar waren gestegen met gemiddeld 0,9 procent per jaar, maar dat het percentage van het bruto nationaal product in 2015 14 procent bedroeg en voor het derde jaar op rij gedaald was (CBS, *Zorguitgaven stijgen langzamer*, 2016). In het jaarverslag 2015 van het ministerie van Volksgezondheid, Welzijn en Sport (VWS) was te lezen dat minister Schippers de kosten weliswaar onder controle heeft, maar zich nog altijd volop inzet om deze verder te beperken (Rijksoverheid, 2016 c).

Een derde ontwikkeling binnen de GGZ, die ook in relatie tot de eerste twee punten staat, is de (politieke) keuze om binnen de zorg te focussen op het intensiveren van de samenwerking gelijktijdig met het beheersen van de kosten. Dit blijkt niet zo simpel te zijn. Ondanks dat deze ontwikkeling van meer samenwerking veel positieve waardering krijgt, blijkt het in de praktijk behoorlijk complex. Dit heeft onder andere te maken met het brede palet aan perspectieven binnen de zorg. Alleen al de theoretische achtergrond van een psychiater, een gz-psycholoog en een sociaalpsychiatrisch verpleegkundige verschilt enorm. De samenwerking met de huisarts, de POH-GGZ, de jeugdzorgmedewerkers en de sociale wijkteams wordt bemoeilijkt door het verschil in opleidingsachtergrond, geleerde methodiek en rol in het zorgstelsel. De daadwerkelijke verandering, zoals bedoeld door de politiek, dient uiteindelijk gemaakt te worden in de spreekkamer tussen behandelaar en patiënt. Hier worden alle losse eindjes van het zorgstelsel gevoeld en sommige daarvan worden ervaren als ethische dilemma's. Helaas is er in een tijd waar 'meten is weten' geldt, nauwelijks ruimte voor ethische zorgvraagstukken (Centrum voor Ethiek en Gezondheid, 2004).

De ambivalente opdracht aan bestuurders in de zorg is de vierde ontwikkeling. Bestuurders moeten enerzijds denken binnen economische modellen die vooral uitgaan van groei en vooruitgang, terwijl de feitelijke opdracht krimpen is. Krimp van het zorgaanbod (aantal bedden), krimp van het personeel (bezuinigingen) en ten tijde van krimp juist groei van de overhead om te voldoen aan de landelijke en/of contractuele eisen van de zorgfinanciers. Dit is geen gemakkelijke opgave. Tel daarbij ook de voortdurende technologische ontwikkelingen mee. Deze

technologische ontwikkelingen bevestigen het beeld van vooruitgang maar de meerwaarde gerelateerd aan de kosten staat nog volop ter discussie (Van der Lugt, 2016). De wankele financiële positie en de groei van de administratieve lasten, ten vijfde, verhoogt eveneens de complexiteit van veel zorginstellingen. Er is veel onduidelijkheid over de declaraties en een toename van de verantwoordingen die instellingen moeten afleggen. Hierdoor lukt het steeds meer instellingen niet om op tijd de jaarrekening in te dienen (GGZNieuws, 2016). Er lijkt ook een duidelijke relatie te zijn tussen de toegenomen administratieve lasten ten behoeve van de verantwoording en het gebrek aan vertrouwen van zorgfinanciers. Minister Schippers van VWS geeft in haar *Kamerbrief meerjarige contracten zorgverzekeringswet* de volgende punten aan: 'gebrek aan onderling vertrouwen, onrust in bekostigings- en productstructuur, schotten in de bekostiging tussen verschillende zorgsoorten en frictiekosten die ontstaan bij veranderingen' (*Kamerstukken II 2015/16, 31765–213*). In het algemeen overleg van de Tweede Kamer over de GGZ (26 mei 2016) kwam deze administratieve druk daarom ook uitgebreid aan de orde. Als het alleen al gaat om de transitie jeugdzorg, blijken de administratieve kosten met ruim tien procent te zijn gestegen (GGZNederland, 2016). Deze toegenomen administratieve druk heeft tevens een negatief effect op de werkdruk van behandelaren. Uit onderzoek van het Nederlands instituut voor onderzoek van de gezondheidszorg (NIVEL) over *De aantrekkelijkheid van werken in de zorg 2015, Cijfers en trends* blijkt dat zorgverleners relatief ontevreden zijn over de tijd die zij besteden aan administratief werk: slechts 23% vindt deze hoeveelheid tijd redelijk en denkt dat patiënten hier geen nadeel van ondervinden (Maurits, De Veer, Spreuwenberg & Francke, 2016). Uit recent onderzoek van organisatieadviesbureau Berenschot blijkt dat gemiddeld 25% van de werktijd van zorgprofessionals opgaat aan administratieve werkzaamheden. Dit is 10% meer dan wat deze zorgprofessionals zelf acceptabel vinden (Zorgvisie, 2016).

Samengevat kan worden gesteld dat het bieden en organiseren van christelijke geneeskundige geestelijke gezondheidszorg veel meer omvat dan het bieden van medische onderzoeks- en behandelingsmogelijkheden die gericht zijn op herstel of voorkoming van verergering van een psychische stoornis. Voor patiënten zijn er meerdere hersteldimensies van belang, waaronder zingeving (religiositeit) en voor zorgorganisaties zijn diverse organisatorische en economische factoren van invloed op het organiseren van zorg. Alle hierboven beschreven elementen van de GGZ staan onderling in verbinding, beïnvloeden elkaar en maken het geheel *complex*. In de volgende hoofdstuk wordt dieper ingegaan op deze complexiteit, met name van de zorgorganisatie.

## *De complexiteit van de Christelijke Geestelijke Gezondheidszorg*

Wanneer je de complexiteit van het bieden en organiseren van geneeskundige geestelijke gezondheidszorg erkent, is de volgende vraag hoe je kunt omgaan met deze complexiteit. Is dit volgens de klassieke wetenschappelijke methodes en modellen of met behulp van complexity sciences? Volgens de klassieke (Newtoniaanse) wetenschap bestaat er een objectieve wereld die door systematisch wetenschappelijk onderzoek ontdekt kan worden. Eenmaal ontdekt kunnen er voorspellingen voor de toekomst worden gedaan. Het reductionisme verdeelt complexe situaties en/of omstandigheden in meetbare objectieve onderdelen, waarbij de invloed van het meetinstrument en/of de onderzoeker nauwelijks aandacht krijgt (Smit, 2015). Het complexiteitsdenken kan worden gezien als reactie op de beperkingen van de op Newton gebaseerde wetenschappelijke methode (Dolnick, 2011). Complexiteitsdenkers proberen helder te maken dat het reductionisme ons veel kennis heeft opgeleverd, maar dat de zoektocht naar gereduceerde objectieve elementen ons nauwelijks kennis biedt over de samenhang en de dynamiek hiervan.

We moeten naar nieuwe invalshoeken kijken om deze complexiteit te kunnen bevatten. Edgar Morin, een Franse filosoof en socioloog en een toonaangevend complexiteitsdenker, beschrijft dit als volgt:

*We need a kind of thinking that reconnects that which is disjointed and compartmentalized, that respects diversity as it recognizes unity, and that tries to discern interdependencies. We need a radical thinking (which gets to the root of problems), a multidimensional thinking, and an organizational or systemic thinking. (Morin, 2008 p. vii)*

Complex wordt in het dagelijkse taalgebruik gezien als iets ingewikkelds, als iets waar 'geen touw aan vast te knopen' is. Ook binnen de *complexity sciences* is hier geen uniforme definitie voor. Volgens Dave Snowden is iets complex wanneer oorzaak en gevolg alleen retrospectief kenbaar zijn (Snowden, 2000). Snowden heeft een '*knowledge and sense making model*' ontwikkeld waarin verhelderd wordt dat complexe situaties om andere interventies vragen dan chaotische of gecompliceerde situaties (Snowden, 2007). Hij noemt dit model het *Cynefin Framework*. Snowden onderscheidt vier systemen in zijn model: simpele, gecompliceerde, complexe en chaotische systemen. Elk domein heeft een eigen oorzaak-gevolgrelatie en behoeft een eigen respons.

Bij **simpele situaties** is de oorzaak-gevolgrelatie helder en bekend. Beschikbare informatie dient gecategoriseerd te worden, waarna er gehandeld kan worden. Bijvoorbeeld: de kosten van de zorginstelling stijgen sterker dan de inkomsten. Dat betekent dat er

óf in de kosten moet worden gesneden óf dat de inkomsten moeten worden verhoogd. De kennis hoe deze informatie gecategoriseerd kan worden en de manieren waarop dit aangepakt kan worden zijn bekend en beschikbaar. Het handelen, wat te doen, is logisch en invoelbaar.

Bij **gecompliceerde situaties** is er wel een oorzaak–gevolgrelatie kenbaar, maar deze ligt minder voor de hand. Ze is niet direct kenbaar: er zit enige tijd tussen, of externe factoren spelen (ook) een rol. Bijvoorbeeld: het ziekteverzuim van een bepaalde afdeling ligt structureel hoger in vergelijking met andere afdelingen. Iedereen heeft wel een idee waardoor dit zou kunnen komen, maar om vast te stellen wat de oorzaak is, is nader onderzoek en professionele expertise vereist. Er dient vervolgens gehandeld te worden op basis van beschikbare kennis.

**Complexe situaties** zijn situaties met unieke eigenschappen, waarvan de oorzaak–gevolgrelatie pas retrospectief kenbaar worden. Er zijn zoveel factoren die elkaar wederzijds beïnvloeden, dat het verloop van de situatie onvoorspelbaar is. Omdat elke complexe situatie een eigen dynamiek kent (de wijze waarop de factoren elkaar beïnvloeden), is het categoriseren en analyseren weinig effectief. De analyse van vorige week kan in een dynamische omgeving volgende week al achterhaald zijn. Kleine wijzigingen kunnen grote effecten hebben. Het categoriseren ligt niet voor de hand; het toch categoriseren verhoogt de complexiteit en voelt kunstmatig en onrealistisch aan (Kurtz & Snowden, 2003). In complexe situaties is het dan ook zinvol om beheerst en creatief met ‘safe fail experiments’ aan de gang te gaan, dus na diepgaand onderzoek interventies uit te proberen en goed in de gaten te houden of er iets verandert in de dynamiek van de situatie. Bij een gewenste verandering kan de interventie worden voortgezet, anders kan de situatie opnieuw worden beoordeeld. Bij een ongewenste of onvoldoende verandering dienen andere interventies ingezet te worden. Het doel is om van een complexe situatie naar een gecompliceerde situatie over te kunnen gaan. Een voorbeeld van een complexe situatie is wanneer twee zorgorganisaties bezig zijn met een voorgenomen fusietraject, waarbij één van de fusiepartners zich onverwachts in een chaotische situatie bevindt en zich genoodzaakt ziet, zich te laten overnemen door een derde partij. Voor de andere organisatie is oorzaak en gevolg op dat moment niet kenbaar. Na verloop van tijd, wanneer meer informatie beschikbaar komt, kan de situatie gereconstrueerd worden, waarbij oorzaak en gevolg kenbaar worden.

Bij **chaotische situaties** is de oorzaak–gevolgrelatie onbekend. Er is sprake van een onwillekeurige samenloop van omstandigheden, waarbij zelfs retrospectief geen oorzaak–gevolgrelatie zichtbaar wordt. In chaotische situaties is het van belang om de situatie zo spoedig mogelijk te stabiliseren, door zo snel mogelijk te handelen. Dit kan door een aantal deelsystemen in de chaotische situatie als geïsoleerde (gecompliceerde)

problemen te behandelen, waarbij wel sterk wordt gelet op de betekenis hiervan op de dynamiek binnen de chaos. Een voorbeeld is de transitie van de jeugdzorg naar de gemeenten. Hoewel de visie achter deze transitie door veel partijen wordt gesteund, is de omvang van de transitie van dusdanige proporties met een grote diversiteit aan variabelen, dat het verloop en de uitkomst zich niet eenduidig laten voorspellen. In chaotische situaties gaat het om 'niet-kenbare' situaties waar onvoldoende kennis voorhanden is.

Wanneer we alle ontwikkelingen waar een zorgorganisatie binnen de GGZ mee te maken heeft, zoals beschreven in het eerste deel van dit artikel, in ogenschouw nemen dan is het aannemelijk te stellen dat de GGZ zich bevindt in een complexe situatie, er sprake is van een complex systeem. Omdat er in dit complexe systeem veel 'agents' (individuen, groepen, organisaties) zitten die individueel en als groep reageren op de dynamiek (zelforganisatie) is er sprake van een complex adaptief systeem (CAS). Een CAS in staat is zich aan te passen aan veranderingen vanuit een vorm van zelforganisatie (Holland, 2006). Het gaat er hierbij om dat het complexe systeem (de zorgorganisatie) ruimte biedt om de medewerkers zich aan te passen aan de veranderende omstandigheden zonder dat deze veranderingen door de leiding worden bedacht en uitgerold (Andersons, 2000, Plsek, 2001, Sturmberg, 2010, Heylighen, 2013). Hier wordt later, bij de lerende organisatie dieper op in gegaan.

### *Traditionele organisatiemodellen*

Wanneer we het *Cynefin Framework* vertalen naar de complexiteit van het besturen van een zorgorganisatie binnen de GGZ, dan kunnen we stellen dat de complexiteit te vinden is in de dynamiek tussen diverse aspecten van en perspectieven op de GGZ. In zijn Normatieve Praktijkenmodel onderscheidt Glas kwalificerende, funderende en conditionerende aspecten aan de zorgpraktijk (Glas, 2009). Het is complex om bestuurlijk recht te doen aan alle aspecten. Traditionele organisatiemodellen zijn doorgaans ontoereikend, omdat zij deze complexiteit het hoofd willen bieden door middel van 'trial and error, het ontkennen van de complexiteit, de complexiteit proberen te begrijpen om daarmee de context voorspelbaar te maken of door de complexiteit te versimpelen' (Snippe, 2014 p. 26). Traditionele organisatiemodellen zijn gebaseerd op het opknippen van de organisatie in overzichtelijke eenheden. De afdeling zorgadministratie administreert en controleert de noodzakelijke administratieve handelingen, de afdeling Kwaliteitszorg bewaakt het Kwaliteitsmanagementsysteem en het team hoofdbehandelaren bespreekt de inhoudelijke zorgvraagstukken. Wil je als complexe zorgorganisatie echter bestuurlijk recht doen aan deze complexiteit, dan dient de zorgorganisatie zich te kunnen gedragen als een complex adaptief systeem. Dit betekent allereerst accepteren dat een centraal



managementsysteem veranderingen intern en extern onvoldoende kan voorspellen en stabiliseren (Snippe, 2014). Inzicht hebben in de gehele interne en externe dynamiek is een utopie. Daarom dient er gebruik gemaakt te worden van interne en externe netwerkintelligentie. Leiderschap verliest daarmee de functie van op grond van eigen waarnemingen en kennis beslissingen nemen en vervolgens vertellen welke koers er gevaren dient te worden. Het netwerk neemt de kennismacht van het centrale managementsysteem over. Op basis van netwerkintelligentie zal de strateeg op een paar hoofdpunten de strategie van een bedrijf bepalen. De sociale systemen bepalen door middel van netwerkintelligentie vervolgens hoe zij het beste gehoor aan deze strategie kunnen geven. (Snippe, 2014 p. 179).

Snippe beschrijft hier dat het besturen van een complexe (zorg)organisatie niet vanuit een centraal managementsysteem dient te gebeuren, maar dat er een netwerk van informatie door de gehele organisatie ontwikkeld moet worden. Dit netwerk omvat elementen van het adaptief vermogen van de medewerkers. Er dient volop gebruik gemaakt te worden van alle aanwezige kennis binnen de organisatie, waarbij het centrale management tot taak heeft het delen van bestaande kennis en het stimuleren nieuwe kennis te ontwikkelen. Zo wordt toegewerkt naar een *lerende organisatie*.

### *De lerende zorgorganisatie*

Peter Senge kan als de *founding father* van de lerende organisatie gezien worden. Hij omschrijft een lerende organisatie als volgt:

*Organisaties waarin de mensen steeds beter in worden om dat tot stand te brengen wat ze werkelijk willen, die een voedingsbodem zijn voor nieuwe, steeds meer omvattende ideeën, waar een gezamenlijk streven mogelijk wordt en waar mensen voortdurend leren hoe ze samen kunnen leren. (Senge, 1992, p. 9).*

Een lerende organisatie is een organisatie waarin het adaptief vermogen van de medewerkers en/of teams worden benut en gestimuleerd. Een lerende organisatie hanteert, volgens Senge, een vijftal elementaire disciplines.

**Persoonlijk meesterschap:** voortdurend de persoonlijke visie verhelderen en verdiepen, gefocust blijven en geduld hebben om zo een hogere graad van meesterschap te ontwikkelen.

**Mentale modellen:** bewust zijn van diepgewortelde veronderstellingen, generalisaties of beelden die van invloed zijn op ons perspectief en handelen.

**Gezamenlijke visie:** op basis van een gezamenlijke visie handelen medewerkers omdat ze het willen in plaats van omdat het moet. Een gezamenlijk toekomstbeeld voedt het engagement.

**Teamleren** benadrukt het gezamenlijk denken en leren in plaats van het evenwicht tussen de individuele intelligentie binnen het team. Teams vormen de kern van de netwerkintelligentie.

**Systeendenken** verbindt – zoals Morin dit ook verwoordt – datgene wat onsamenhangend en gecompartmenteerd is. Het maakt grotere patronen zichtbaar en het leert de dynamische complexiteit begrijpen, in plaats van de complexiteit van details. Senge heeft het ook over 'metanoia', oftewel geestesverandering. Metanoia betekent een verschuiving in het denken. Dit sluit aan bij de betekenis van metanoia vanuit een christelijk perspectief, waar het bezinning, een verandering van gedachten en het verkrijgen van beter inzicht betekent.

### *De lerende zorgprofessional*

Een lerende organisatie biedt de ruimte om te kunnen reageren op complexe omstandigheden. Een lerende organisatie, met deze vijf disciplines, benut op deze wijze het adaptief vermogen van haar medewerkers. Organisaties kunnen slechts leren wanneer hun medewerkers leren. Lerende individuen vormen weliswaar geen garantie voor lerende organisaties, maar wel een noodzakelijke voorwaarde (Senge, 1992, p. 137). Op het niveau van de zorgprofessional, als medewerker van een lerende organisatie, is de discipline van persoonlijk meesterschap een prominente discipline. Persoonlijk meesterschap stimuleert het vermogen om de resultaten tot stand te brengen die men werkelijk belangrijk vindt. Persoonlijk meesterschap staat voor een groter engagement, meer initiatief en een snel lerend vermogen. Persoonlijk meesterschap, gezien in het licht van de herstel georiënteerde zorg vanuit een christelijke visie, maakt helder dat er veel van de zorgprofessionals wordt gevraagd. Zij moeten in staat zijn om medische onderzoeks- en behandelingen gericht op herstel of voorkoming van verergering van een psychische stoornis uit te voeren. Zij dienen mee te werken aan de grote hoeveelheid bureaucratische regels en aan het betaalbaar houden van de zorg. Hun behandelingen moet voldoen aan de stand van de wetenschap, en dient te leiden tot positieve behandelresultaten en een tevreden patiënt. Tot slot, maar minstens zo belangrijk, dienen zij de christelijke visie uit te dragen en zich bewust te zijn van de eigen opvattingen

over het geloof. Per saldo betekent dit dat er een grote diversiteit aan waarden is waarmee de zorgprofessional rekening dient te houden. Van medisch-ethische waarden tot aan wetenschappelijke waarden, van persoonlijke waarden tot economische en sociaal-maatschappelijke waarden. En van algemeen christelijke waarden vanuit de zorgorganisatie tot aan de persoonlijke geloofswaarden.

Wanneer er een veelvoud aan ethische opvattingen is, spreek je van een *ethisch pluralisme*. Ethisch pluralisme of ethische diversiteit is het tegenovergestelde van een ethisch monisme, waar slechts één ethische visie (samenhang van aantal waarden) overheerst en waaraan andere ethische waarden ondergeschikt zijn. Volgens Isaiah Berlin, een Brits politiek filosoof, zijn er geen alom geldende universele waarden waarbij al ons denken en handelen samenvalt. Er zijn weliswaar een aantal universele basiswaarden, maar die vallen niet samen met al ons handelen. Wanneer er gestreefd wordt naar een ethisch pluralisme, waarbij de diverse waarden in principe gelijkwaardig zijn, is er meer ruimte voor tolerantie bij de persoonlijke invulling van deze waarden.

*If pluralism is a valid view, and respect between systems of values which are not necessarily hostile to each other is possible, then toleration and liberal consequences follow, as they do not either from monism (only one set of values is true, all the others are false) or from relativism (my values are mine, yours are yours, and if we clash, too bad, neither of us can claim to be right). (Berlin, 1998, p. 13)*

Thomas Nigél, een Amerikaanse filosoof voegt er aan toe dat ethische waarden ook altijd een persoonlijk karakter hebben en niet gestandaardiseerd kunnen worden. Dat wij weliswaar de neiging hebben de wereld objectief te begrijpen, maar dat dit tegelijkertijd een onmogelijkheid is (Nigél, 1974). Dit betekent dat er een natuurlijk spanningsveld is tussen bijvoorbeeld de eigen geloofsbeleving en de algemeen omschreven christelijke visie op zorg. Ethisch pluralisme betekent enerzijds dat de diverse waarden gerespecteerd dienen te worden, en anderzijds dat wij met elkaar in dialoog moeten blijven over deze (mogelijk tegenstrijdige) waarden. Om als zorgprofessional uitvoering te geven aan de herstelgeoriënteerde zorg vanuit een christelijke visie vanuit het perspectief van persoonlijk meesterschap, zou je in staat moeten zijn om de diverse (mogelijk tegenstrijdige) waarden te verhelderen en te verdiepen. Dit is een complex vraagstuk!

## *Amor complexitatis*

Zorgprofessionals bevinden zich dus in een complex zorgsysteem, hebben te maken met een diversiteit aan waarden in een context die veelal uitgaat van een ethisch monisme, moeten de visie vanuit het biomedisch model met zingevingsvraagstukken combineren, enz. Dat is complex! De gemiddelde mens houdt echter niet zo van complexiteit, hij heeft een voorkeur voor orde. De hier boven reeds aangehaalde Edgar Morin stelt:

*We have an unconscious tendency to push out of our minds what contradicts it, in politics as in philosophy. We will minimize or reject contrary arguments. We will focus selective attention on what favors our idea and selective inattention to what is unfavorable. (Morin, 2008 p. 47)*

De mens heeft, zoals David Hume beschreef, de neiging om een constante conjunctie als een causale reactie te zien (Hume, 2007). Hij observeert A, en op basis van zijn gewoonten (geheugen, eerdere ervaringen) neemt hij B waar als effect. Dit maakt het bekijken van een complexe situatie vanuit verschillende perspectieven en op basis van diverse waarden lastig. Tel daarbij op dat de mens lijdt aan '*inattentional blindness*', zoals het gorilla-experiment van Simons en Chabris heeft aangetoond (Simons & Chabris, 1999). Hiermee wordt bedoeld dat wanneer iemand gericht is op het ene, hij het andere onbedoeld niet ziet. Wanneer een zorgprofessional bijvoorbeeld gefocust is op de klinische symptomen van de patiënt, kunnen existentiële vraagstukken onopgemerkt blijven.

Deze menselijke beperkingen moeten niet worden opgelost, maar vooral onder ogen worden gezien volgens Kunneman. Harry Kunneman, Hoogleraar Sociale filosofie nodigt de professional daarom uit om deze complexiteit niet uit de weg te gaan, maar er als het ware van te houden: *amor complexitatis*. 'Deze eigentijdse *amor complexitatis* berust op het verbinden van morele, epistemologische en ambachtelijke hulpbronnen met het oog op goed werk in moerassige condities' (Kunneman, 2013, pp. 448–449). Kunneman gebruikt ook wel de term 'leerzame wrijving', hier kunnen nieuwe perspectieven ontwikkeld worden en verkokering kan worden tegengegaan (Kunneman, 2005). Juist in een tijd waarin de zorg als economisch product wordt gezien, bij voorkeur op basis van gestandaardiseerde zorgprogramma's wordt aangeboden en dit slecht te verenigen voelt met zorg vanuit een christelijke visie (bewogenheid met mensen die lijden vanuit Gods liefde voor mensen), komt het aan op persoonlijk meesterschap gecombineerd met *amor complexitatis*. Volgens Senge uit het persoonlijk meesterschap zich in twee ontwikkelingen. 'De eerste is het

steeds duidelijk voor ogen houden wat belangrijk voor ons is. (...) De tweede is het voortdurend leren hoe we de actuele werkelijkheid duidelijker kunnen zien' (Senge, 1992, pag. 139). Dit vormt als het ware de leeropdracht voor de zorgprofessional. De complexiteit dient verdragen te worden, het vermogen om de resultaten tot stand te brengen die men werkelijk belangrijk vindt dient gestimuleerd te worden, en op basis van het teamleren dient de eigen en de professionele visie op de geloofsbeleving verhelderd en verdiept te worden.

### *Conclusie en discussie*

Voor de zorgprofessional, werkzaam bij een zorgorganisatie voor christelijke GGZ, betekent de herstelgeoriënteerde zorg vanuit een christelijke visie vooral dat er een groot beroep wordt gedaan op diens persoonlijk meesterschap, een van de disciplines van de lerende organisatie. Als zorgprofessional word je dagelijks geconfronteerd met de complexiteit van het bieden van christelijke zorg. Het is van belang dat je als zorgprofessional de ruimte krijgt hier adaptief mee om te gaan maar ook dat je leert houden van deze complexiteit.

Met de analyse dat adaptief vermogen en teamleren binnen een complexe christelijke organisatie nodig zijn, is natuurlijk nog niet de vraag beantwoord of zorgprofessionals daarvoor voldoende zijn opgeleid. Ook adaptief vermogen en teamleren moeten geleerd worden. Vanuit deze analyse van wat nodig is, is de volgende vraag of zorgopleidingen daarvoor de goede professionele voorwaarden willen scheppen.

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## Chapter 9

### The complexity of healthcare fraud – ethical and practical considerations

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## *Abstract*

When healthcare professionals suspect that healthcare fraud is being committed, they almost always find themselves in a new, unknown situation. They have many questions and feel unable to act adequately. With a growing attention on healthcare fraud, research was done on *What is the right thing to do in case of presumed healthcare fraud and how to do this right?* We started with a search of the literature on healthcare fraud, and the characteristics of a fraudster and a whistle-blower. For 'doing the right thing' we used Hannah Arendt and her distinction between labor, work and action. According to Arendt, the right thing to do is action. With action, the whistle-blower opens up space for other perspectives and discussion. For 'doing things right' we used the Cynefin Framework from Dave Snowden, which is based on complexity sciences. The decision model of the Cynefin Framework gives advice on how to respond. Still, revealing healthcare fraud and doing things right will always be a path of painful uncertainty.

**Key words:** Ethics, healthcare fraud, whistle-blower, complexity.

## *Introduction*

When healthcare professionals suspect that healthcare fraud is being committed, they almost always find themselves in a new, unknown situation. They may have many questions and feel unable to act adequately. Have I properly seen and/or understood the suspected healthcare fraud? What am I supposed to do now? How do I know that I am doing the right thing for the right reasons? Can I speak about my suspicions without doing harm? Doing nothing is sometimes not an option. But what is the right thing to do and how can one act in the right way?

Our research question looks at 'doing the right thing' and 'doing things right' in the case of healthcare professionals suspecting healthcare fraud. The focus lies specifically on cases where the presumed fraudster (healthcare management, board) and the potential whistle-blower (healthcare professional) have a hierarchical relationship. For 'doing the right thing' we refer to Hanna Arendt and her distinction between labor, work and action. For 'doing things right' among other sources we refer to the Cynefin Framework by Dave Snowden, which is based on complexity sciences. We begin with a search of the literature on healthcare fraud, and the characteristics of a fraudster and a whistle-blower.

## *Healthcare fraud*

The European Commission (2013) defines fraud as “a benefit of any nature by intentionally breaking a rule.” The European Healthcare Fraud and Corruption Network (EHFCN) distinguishes four types of fraud (EHFCN 2016:10): first, charging for excessively expensive care; second, charging for services not provided; third, providing unnecessary services; and fourth, other forms of fraud or corruption, including charging individual payments for public services and fraudulent contracts and procurement practices. Besides fraud, a distinction can be made between errors, abuse and corruption in healthcare. The EHFCN describes errors in healthcare as “unjustly obtaining a benefit of any nature by unintentionally breaking a rule” (EHFCN 2016:178). Abuse is described as “unjustly obtaining a benefit of any nature by knowingly stretching a rule or by taking advantage of an absence of rule” (*idem*). And, corruption can be defined as “illegally obtaining a benefit of any nature by abuse of power with third party involvement” (*idem*).

Thorton, Brinkhuis, Amrit and Aly (2015) categorized several types of fraud in healthcare, finding that improper coding, phantom bills and kickback schemes were the most frequent forms. Improper coding, or upcoding, is the most discussed and prevalent topic according to Thorton. In the case of upcoding, the healthcare provider claims more refunds than appropriate for the care provided. When phantom billing is the case, invoices are issued for care that has not been delivered. Kickback schemes are the case when, for instance, a psychiatrist fills a prescription with a specific brand of drug to benefit from a bonus from the pharmaceutical company.

Thompson (2013) draws a distinction between individual and institutional corruption. Individual corruption, Thompson explains, is the *personal* gain of individuals, while giving care within a healthcare facility. Institutional corruption is seen as the failure of the *institution* in preventing healthcare fraud. Brooks, Tunley, Button and Gee (2017) argue that while it is useful to have a clear definition of healthcare fraud to combat this kind of fraud, having a clear definition will not solve [all] problems with healthcare fraud in Europe. Every country will still be faced with different interpretations, laws and political will. Healthcare fraud activities may also be seriously obstructed by regulations, especially where the rules are complex and uncertain (as described in Portugal, Slovenia and the Netherlands), provide insufficient competences for supervisory bodies – especially in relation to privacy legislation (Italy, Netherlands) and finally, when these rules are subject to frequent changes, leading to a situation of uncertainty as the report on Lithuania indicates (Sauter, Mikkers, Vincke & Boertjens 2017:17).

The definitions of healthcare fraud listed above are all more or less about breaking the rules. When a healthcare professional initially suspects that healthcare fraud is being committed, the meaning and correct interpretation of all information is not at the forefront of the professional's mind. A healthcare professional is neither an administrator nor a healthcare lawyer. Also, the distinctions between intentionally or unintentionally breaking rules and between personal benefit and institutional benefit are hard to judge up front. In addition, the rules, the policy and the law with regard to billing in the healthcare sector are often up for discussion. All of this creates a gray area filled with uncertainty. An unequivocal definition of fraud and corruption remains elusive and stays relative because our understanding of fraud and/or corruption is rooted in the social, political and cultural context (Brooks, Tunley, Button & Gee 2017).

### *The fraudster*

To be a fraudster in a healthcare setting, you do not need to be a healthcare professional. A fraudster can be a healthcare administrator, a manager, a director or major shareholder, and [of course] patients can also be fraudsters. In this research we focus on fraudsters who have a hierarchical relationship with the potential whistle-blower.

What do we know about fraudsters, about their motives, their characteristics? Brooks, Tunley, Button & Gee (2017) describe what could be incentives for the fraudster. But first they note that healthcare fraud is often termed white-collar crime. In contrast to street crime, where the offender is seen as a criminal driven by 'cognitively defective constitutions', the white-collar fraudster is often seen as a respectable entrepreneur. White-collar crime often goes undetected and if detected, white-collar criminals are not always prosecuted and convicted. Cressy (1950) claims that the most likely reasons why a fraudster acts fraudulently is because they are under pressure, have the opportunity to commit fraud and can rationalize their acts. Brooks, Tunley, Button & Gee (2017) state that fraudsters create a wall of justification; they diminish the impact and seriousness of their acts. According to Ogunbanjo & van Bogaert (2014), healthcare fraudsters rationalize their acts by considering healthcare fraud to be a victimless crime, that the organization is not harmed by their acts. "A rationalization is not an after-the-fact excuse that a perpetrator uses to justify his or her behaviour, but an integral part of the actor's motivation for the act" (Coleman 1987: 411). Sorunke (2016) adds that the fraudster's capability to commit fraud is another key motivating factor. Sorunke explains that a person with low personal ethics does not even have to be confronted by pressure to commit fraud. Their personal ethics can be enough to make use of opportunities to commit fraud. Here the distinction between white-collar crime and street crime becomes very thin. Nevertheless, to commit fraud – a criminal act –

there must be an intention to act inappropriately. Only when an act is characterized as “willful intent to deceive and profit from the deception” can it be prosecuted as fraud (Byrd, Powell & Smith 2013). According to Ainsworth (2001), there need to be a motivated offender, a suitable (and vulnerable) victim and the absence of a capable guardian for a crime to be committed.

In summary, fraud in healthcare settings is often regarded as white-collar crime. The fraudster is most likely under pressure to be successful, is capable of rationalizing their acts and probably has low personal ethics. However, to commit fraud in the legal sense, a willful intent to deceive and profit from the deception must be proven.

### *The whistle-blower*

The term ‘whistle-blower’ can be traced back to the 19th century (Martin n.d.). In those days it was normal for a policeman to blow a whistle when detecting a possible crime. By blowing the whistle, the police officer could warn the public and fellow officers. The story goes that the term whistle-blower was used to avoid terms with more negative connotations, such as ‘snitch’ and ‘informer’ (Nader 1972). Journalists began using the term in the 1960s. Martin defines the term as a “person who tries to raise the alarm about a problem and publicizes it inside and/or outside of his/her organization” (Martin n.d.).

Do whistle-blowers have particular identifying characteristics? Starkey (2000) finds little support for dispositional variables on whistle-blowers but did find situational variables that could predict the intention to blow the whistle. In other words, a situation can make a person a whistle-blower, not the specific characteristics of a person. This fits the idea that one *is* not a whistle-blower, but one can *become* a whistle-blower, for example when people in power would rather not reveal (possible) healthcare fraud. Whistle-blowers act in complex and contested circumstances (Mannion & Davis 2015). Personal idiosyncrasies play a role, also whether or not the whistle-blower will be seen as a hero or troublemaker (*idem*). Even when the whistle-blower is seen as a hero, seldom do they live ‘happily ever after’.

Whistle-blowers are normally subjected to hostility and retaliation in the form of intimidation, harassment, reprisal, dismissal and violence by their fellow colleagues and superiors and in the worst circumstances, even death (Sehgal 2017:267).

The forces released when whistle-blowers have no anonymity are many times greater. The bottom line is that such a person is destroyed by the people who want to keep the information under wraps, as I dare say after more than eighteen years of experience with whistleblowers (Smit 2017).

Purmina Sehgal (2017) collected the stories of well-known whistle-blowers. These whistle-blowers include Daniel Ellsberg (Pentagon Papers during the Vietnam War), Stephen Bolsin (an anesthetist who disclosed the unnecessary death of children after open heart surgery), and Jeffrey Wigand (who revealed that tobacco companies were intentionally manipulating nicotine levels to addict smokers). Sharron Watkins (Enron), Coleen Rowley (FBI) and Cynthia Cooper (WorldCom) all exposed malpractices and manipulations, as did Bradley Manning and Edward Snowden (WikiLeaks). All their stories are about lawyers, financial problems, persistence, loss of friends, psycho-social problems and so on. Some whistle-blowers, like Satyendra Dubey (National Highways Authority India), Shanmughan Manjunath (adulterated fuel) and SP Manhantesh (reported irregularities in society involving officials and political figures) were even murdered. In the Netherlands there was a whistle-blower case at the Dutch Healthcare Authority (NZa). Arthur Gotlieb worked at the NZa as a policy advisor responsible for expensive medicine. He had reasons to believe that his supervisor(s) were too sensitive to lobbying by pharmaceutical companies. At first he followed the internal procedures to discuss his concerns but this only led to him being lumbered with new and especially impossible tasks at which he had to fail. This, in turn, led to an intern-supported attempt to get him fired or replaced. Although Gotlieb had documented all his concerns with evidence (e.g. e-mails and business weekend trips unreimbursed by the NZa) his employer gave him no support. Soon after he had presented his report to the managers, he committed suicide (Kalcheva 2015). Afterwards, the Dutch healthcare minister concluded that Gotlieb had been mistreated and that the NZa had not accepted any criticism.

In summary, although there is little support for dispositional variables on whistle-blowers, one may safely assume that a whistle-blower will have highly developed personal ethics and be tenacious. Perhaps these two qualities are not dispositional variables, but they are likely needed to survive a whistle-blower's position.

### *Doing the right thing*

Whether anyone is a potential fraudster or whistle-blower is not clear at first, to no one. The potential whistle-blower has to make a choice, at an early stage, to discuss the situation or not, and with whom. Making suspected healthcare fraud open to discussion, for the first time, does not necessarily have to escalate the situation, but ultimately it can have major consequences. It is an extremely complex issue where the impact and size are hardly known at the outset. What is the right thing to do at what point? On the one hand, Ogunbanjo & van Bogaert state, "Healthcare fraud is also not a victimless crime. Therefore, healthcare professionals must inform on colleagues who practice it" (Ogunbanjo & van Bogaert 2014:13). But on the other hand, Mannion states that



whistleblowing has “many complex and ambiguous aspects that need to be considered as part of the broader (organisational) cultural dynamics of healthcare institutions” (Mannion 2015:503). Blowing the whistle can have a butterfly effect; a small action can cause major change (Gleick 2011, Dooley 2009). What happens when the suspected fraudster is asked about the alleged fraud is a sensitive matter. The response depends on the initial conditions, which include the relationship between the suspected fraudster and potential whistle-blower: stable/unstable, full of/lacking in confidence and equal/unequal. A small change initiated by a whistle-blower carefully bringing up suspected fraud can result in significant differences later on, as happened in the Gotlieb case. One can think of dismissal, damaged mutual trust or a lawsuit against the whistle-blower. It is therefore quite conceivable that the potential whistle-blower would feel unsure about what is the right thing to do. At the time of the first confrontation with possible fraud, there are no clues as to the scale or impact of this confrontation. In this case, one can fall back on the professional code of ethics, which can be traced back to the Geneva Declaration (based on the Hippocratic oath) and the Code of Medical Ethics. The World Health Organization advises following ethical principles:

**Table 1: Ethical principles pertaining to the World Health Organization.**

<b>Integrity</b>	To behave in accordance with ethical principles, and act in good faith, intellectual honesty and fairness.
<b>Accountability</b>	To take responsibility for one's actions, decisions and their consequences.
<b>Independence and impartiality</b>	To conduct oneself with the interests of WHO only in view and under the sole authority of the Director-General, and to ensure that personal views and convictions do not compromise ethical principles, official duties or the interests of WHO.
<b>Respect</b>	To respect the dignity, worth, equality, diversity and privacy of all persons.
<b>Professional commitment</b>	To demonstrate a high level of professionalism and loyalty to the Organization, its mandate and objectives.

However, in the case of presumed healthcare fraud, the virtues or principles of ‘integrity’ and ‘professional commitment’ can create a field of tension for a potential whistle-blower. In the eyes of the fraudster, acting in accordance to ethical principles (being honest and acting in good faith) may conflict with the interests of the healthcare organization. Uys & Senekal say that whistle-blowers are confronted by a severe dilemma, having to choose between the morality of principle and the morality of loyalty. But, they also claim, “If any of the options were believed to be of higher moral value than the other, then the dilemma would theoretically disappear” (Uys & Senekal 2008:39).

In *Morality of principle versus morality of loyalty: The case of whistleblowing* the authors take a closer look at the distinction between the two moralities developed by Brede-meier & Stephenson (1967).

The morality of loyalty within the organisational context states that it is right or proper for employees to be loyal to their organisations. The morality of principle, on the other hand, defines it as 'morally good' to act in accordance with certain abstract principles (in this context typically the legal or ethical requirements applicable to the organisational context) irrespective of the people involved (Uys & Senekal 2008:39).

In the ideal situation, Uys & Senekal state, congruent morality is the case, and the moralities of principle and loyalty are equal. In the case of healthcare fraud, where there is a fraudster and a whistle-blower, the fraudster deviates from both moralities while the whistle-blower deviates from the morality of loyalty but conforms with the morality of principle. In other words, the whistle-blower puts the morality of principle above the morality of loyalty. Theoretically, as stated above, the whistle-blower no longer has a dilemma. But in most cases, when colleagues still assume that both moralities are equal, deviating from the morality of loyalty does indeed evoke a considerable emotional dilemma. Even if the whistle-blower takes great care in revealing the alleged fraud, colleagues can experience this deviation as disloyalty and distance themselves from the person concerned. The whistle-blower in turn could risk their job and social connection with colleagues. However, doing nothing can result in more healthcare fraud, which can have consequences for the amount of money available for spending on needed care.

To deepen the investigation into this dilemma, it can be useful to refer to the 'vita activa', the distinction Hannah Arendt draws between labor, work and action in her book *The Human Condition* (Arendt 1958):

With the term *vita activa*, I propose to designate three fundamental human activities: labor, work, and action. They are fundamental because each corresponds to one of the basic conditions under which life on earth has been given to man (Arendt 1958:7).

For Arendt, labor is a cyclical process that is necessary for self-preservation and the reproduction of the human species. Work, however, is a linear process with a clear beginning and end. It is what we produce, for instance healthcare, therapy, healthcare management or healthcare administration. Action is the means by which humans disclose themselves and humans can distinguish themselves from others. It includes speech and act; it reveals who you are as a human being. Through action and speech, the unique character traits of a person become apparent. Where labor is cyclic and work

is linear, action has no clear boundaries and can have consequences that cannot be foreseen or can be overlooked. Action has no beginning or end and its consequences can change over time.

To translate this into the case of healthcare fraud and specifically to the question of what is the right thing to do, Arendt's distinction between work and action is relevant. Work is the world of *homo faber* "where everything must be of some use" (Arendt 1958:154). It is about production, in this case producing healthcare within a healthcare organization. Work is about the ability to maintain an environment fit for human use. It is about doing things according to established procedures and customs. The right procedures are taught during vocational training and repeated over time. Matching procedures is the Code of Medical Ethics. In the linear environment of work, you have to follow procedures. They can be internal procedures such as fraud prevention or fraud control procedures or following the Code of Medical Ethics. If a whistle-blower wants to discover what the right thing to do is, they have to follow these procedures, these ethical principles. But in complex cases where much is at stake, simply following procedure is rarely enough. It is not incomprehensible that in unique, complex situations standard procedures and ethical principles will not provide sufficient guidance for the whistle-blower to know what the right thing is to do. What if the internal supervisory board only refers to internal procedures, the fraudster threatens to fire the whistle-blower, or the external state supervisors want to see hard evidence before accepting the case? The potential whistle-blower still does not know what the right thing is to do... Then action comes in. Action is accompanied by uncertainty, unpredictability and irreversibility. If someone blows the whistle by speaking out, they take action. In contrast to the linearity of work, action is the first step of an uncontrollable chain reaction. As Morin says, "The domain of action is very risky, very uncertain. It imposes on us a very keen awareness of risks, derailments, bifurcations, and imposes a reflection on complexity itself" (Morin 2008:55). Action is irreversible. Telling the fraudster that (presumed) fraud has been noticed cannot be undone. The relationship between fraudster and whistle-blower is changed, for better or worse. After action, the reaction – and the chain of following reactions – is unpredictable. Is action something to hold back on because of its unpredictability and irreversibility? According to Arendt, the answer is no. "The fact that man is capable of action means that the unexpected can be expected from him, that he is able to perform what is infinitely improbable" (Arendt 1958:178). This is what makes us rise above the standards of work, with all its guidelines and procedures. From this line of thinking, an action like blowing the whistle is, on the one hand, scary because of its unpredictability and irreversibility. But on the other hand, it is what makes us human. It encourages us to be more than a 'puppet on a string.' In other words, Arendt encourages us to speak out and take action. If we do not want to live only by procedures we have to speak out, we have to take action. Knowing – about fraud – and wanting to be a human means taking

action. Doing the right thing is therefore strongly related to our position in society. This not only applies to whistle-blowers, but to anyone else involved, such as the internal supervisory board, the external state supervisors as well as government and of course the fraudster. At worst, the whistle-blower is the only one who speaks out and acts. But in the best case many more who are involved take action and a dialog is started. The situation can be discussed from different angles and led to a new beginning. The plurality of actors and opinions is needed to understand what is revealed and what it can mean. By sharing different perspectives, we are able to “see reality in the round and develop a shared common sense” (Canovan introducing Arendt 1958:xni).

Whistle-blowers do not own the truth, nor are they just liars. Blowing the whistle is not about revealing fraud or being a hero by definition. Blowing the whistle in suspected healthcare fraud is acting like a socially and politically engaged human being. By taking action, you open up the space for other perspectives and discussion.

This raises a question concerning ‘doing the right thing’. Is there a logical or even necessary sequence in what to do first? Should the healthcare professional who suspects healthcare fraud start by following standard internal procedures within the framework of what Arendt calls work? Then, only if this first step proves insufficient, should the next step can be taken, namely, to switch to external procedures. And if that has insufficient effect should the whistle-blower make the information public? This may suggest that if the whistle-blower does not get their way with the internal procedures, they would seek further. Ultimately, this person risks identifying themselves with the classic image of a whistle-blower: as a victim of those in power. This trajectory starts looking as if it more about being heard or even recognized as a whistle-blower, instead of the disclosure of information to gain more perspectives on this information. When someone speaks out in the public realm, providing information about suspicions of healthcare fraud, and is not open to other perspectives... this person is actually lingering in the social domain of procedures and will feel frustration that things are not going the way they want. This is not what Arendt means by action and becoming “who you are”. Who you are, is formed by the exchange of information in contact with others in the public realm (Arendt 1958). For reality is constituted in the public realm, where there is freedom of action and speech and there is uncertainty as to what others will do with this disclosure of information. Action has to take place in interaction with others. If a whistle-blower does not open up to other perspectives, they do not take action in the sense of what Arendt means by action.

Whistleblowing is emphatically not about making judgments. Although it is tempting to link to whistleblowing in line with Arendt’s ideas about judgment, whistleblowing is about acting and not about judging. If someone who suspects healthcare fraud

keeps quiet, the suspicion lingers proverbially. The suspicion persists, it is not refuted or confirmed. Whistleblowing can start a new discussion and is (just) one of the many perspectives necessary to make a sound judgment.

In summary, a healthcare professional and potential whistle-blower can stay within the lines of *work* and 'just follow procedure'. If nothing changes or the whistle-blower is fired, so be it. But if the healthcare professional wants to be a human being, not just an employee, they should take action. This action entails uncertainty and unpredictability, which can make a whistle-blower feel anxious and vulnerable. It is therefore necessary that the whistle-blower is not the only one who acts and speaks out. *All* involved should take action and speak out. The plurality of opinions and perspectives helps to develop a common sense. In the framework of being human, being socially and politically engaged, action is the right thing to do, and while doing it, one hopes all relevant stakeholders will do it too...

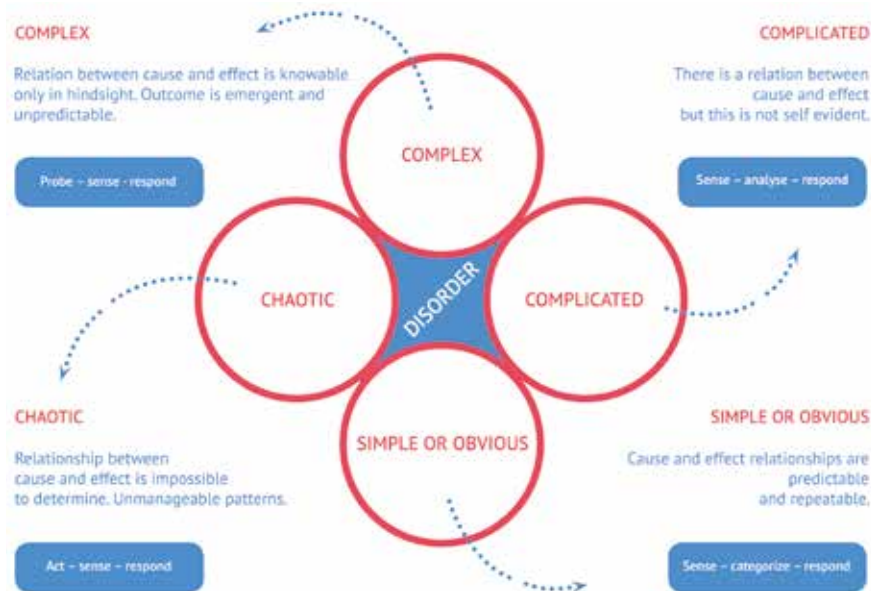
### *Doing things right*

If one blows the whistle, takes action, how should one operate? Where to start and what to do next? In the event of blowing the whistle on suspected healthcare fraud, the situation is complex and dynamic, almost exclusively in every case. A healthcare facility or organization has the key features of a complex adaptive system, meaning that the interactions of all its actors are unpredictable and often unique (Sturmberg & Martin 2010). Different shared values (attractors) are involved (Sturmberg, O'Halloran, & Martin 2012). There are economic interests, scientific guidelines, humanitarian and emotional interests, declaration rules from the health insurer and national statutory rules, each interacting in an unpredictable way. A whistleblowing case is also attached to individuals, with their own professional and personal history, idiosyncrasies and mutual relationships (Mannion & Davies 2015). Each situation is unique, so it is hard to develop a one-size-fits-all plan for blowing the whistle.

Brian Martin (2013) managed to write a practical guide for whistle-blowers, based on what almost all whistleblowing cases have in common. He begins with a warning of pitfalls such as trusting too much, having not enough evidence and not building support. He emphasizes that a whistle-blower must be well prepared. Martin lays stress on what a whistle-blower should expect in consequence. "Whistleblowing can have devastating consequences for health, finances and relationships" (Martin 2013:229). But still, the question remains: where to start and what to do next? Where Martin focuses on pitfalls and learning from previous experiences of fellow sufferers, the Cynefin Framework can be of help in analyzing the complexity of the situation (Kurtz & Snowden 2003,

Snowden & Boone 2007). The decision model of the Cynefin Framework gives advice on how to respond. It can help by categorizing the situation in five domains: 'simple or obvious', 'complicated', 'complex', 'chaotic' and 'disorder/confused'. Every domain has its own cause-effect relationship and needs a different response. This framework will not solve problems but it can guide the whistle-blower while taking action. To be clear, the Cynefin Framework does not start from the feelings and thoughts of the whistle-blower; the situation is the starting point. This is an important distinction because a situation can be simple yet still evoke complex feelings. A situation, in this case a suspected healthcare fraud, consists of many actors who jointly provide a certain dynamic. In this situation, the whistle-blower is just one of the actors.

An essential part of using the Cynefin Framework is to develop a support group, as it is needed to organize the "plurality of actors and opinions to understand what is revealed and what it can mean", in line with Arendt (Canovan introducing Arendt, 1958:xni). Also, in line with Martin, a support group is needed to keep the whistle-blower out of the pitfall of not building support. The support group discusses all the factors that influence the situation and its dynamic. The support group judges which part of the situation fits which domain. In the end, the domain gives the whistle-blower advice on how to respond.



To explain the five domains of the Cynefin Framework and its decision model related to disclosure of healthcare fraud, some practical examples follow. The first domain is *disorder*, when the situation is confusing. Example: in the beginning, when healthcare fraud is suspected, not all information is clear, perspectives switch frequently, and laws

and regulations are mostly unfamiliar. The support group disagrees strongly about where the situation fits in the framework. Individuals in the support group may be inclined to place the situation in their favorite domain. But 'disorder' is also where a good discussion gets started. The decision model advises acknowledging that it is not (yet) clear which part of the situation fits in which domain. After this acknowledgment, it is time to break the situation into smaller parts, make sense of its parts and agree on where each part fits in the framework. Possibly some parts are simple and other parts are complicated, complex or even chaotic.

The second domain is *simple*. Example: charging for services not provided or claiming phantom bills. In this domain the relationship between cause and effect is clear and not open to dispute. There is enough knowledge about the subject. The decision model advises making sense of the given information (e.g. the phantom bill), categorizing that data and responding to existing knowledge. Discuss the facts, for example the phantom bill, with those who are responsible for declarations to the health insurer.

The third domain is *complicated*. Here there is a relationship between cause and effect but on first sight it is not yet fully known or known only by a few. Example: providing unnecessary services or claiming more refunds than appropriate for the care that is given. What is necessary or appropriate and what not is debatable and open to multiple interpretations. In a complicated situation the whistle-blower is dependent on experts. These experts can support the fact-finding and experiments can make cause-effect relationship more apparent. To do the right thing, the decision model advises making sense of all information, analyzing it and responding in accordance with expert advice.

The fourth domain is *complex*. Here too there is a cause-effect relationship, but because of the high number of agents and their underlying interactions the pattern can change over time. This means the pattern is unpredictable and can only be knowable on hindsight. Example: when employees widely support a healthcare vision that is actually a cover for healthcare fraud. Healthcare professionals can be unaware of healthcare fraud because their focus is on the widely supported healthcare vision. Propagating a humane healthcare vision, on the one hand, and healthcare fraud on the other – performed by one's manager – is not what employees expect. The decision model here is to create probes before taking action, in a process of trial and error. To take some small action and see what happens until a pattern becomes clearer. It is necessary to do this from several perspectives, so not only from the perspective of 'he is a fraud' but also from 'he is acting in good faith' or 'he does not know what his acts mean or what the consequences are'. After a while the pattern will become apparent. Does the fraudster often lie or does he act without knowing the rules?

The last domain is *chaos*, where there is no relationship between cause and effect to discover. For the whistle-blower this can arise in an unclear and elusive situation. Example: when the fraudster accuses the whistle-blower of disloyalty and defamation and a lot of uncertainty arises within the team on whom to believe. When a situation is chaotic, one must act 'quickly and decisively'. The whistle-blower can try to gain control over the situation (authoritarian actions) or create their own pattern, for example based on their moral principles.

By using the Cynefin Framework, the whistle-blower tries to unfold the intertwined situation based on the information there is or can be obtained. The puts the situation in focus and the goals are collecting information and different perspectives. The support group organizes the importance of collecting many different perspectives. 'Doing things right' is motivated by the decision model associated with the several domains and based on many different perspectives.

### *Conclusions and discussion*

When a healthcare professional is confronted by possible healthcare fraud, in most cases they will be overwhelmed by opinions, questions and emotions. Whether an act really is fraud depends on many factors and most times is a gray area. Healthcare fraud ranges from unintentionally charging too much for service given to kickback schemes and intentionally upcoding declarations for healthcare providers. Who becomes a whistle-blower is determined by situational variables and not the specific characteristics of a person. However, more than likely a fraudster has several recognizable features, such as low personal ethics and the ability to rationalize their [fraudulent] acts.

Not many stories about whistle-blowers have a happy ending. That is why it is important to reflect on the questions of 'doing the right thing' and 'doing things right'. Someone could limit themselves to what Hannah Arendt calls *work* and only follow procedures. The right thing to do, Arendt promotes, is to act: to speak out and start a discussion on the subject. Blowing the whistle in the case of suspected healthcare fraud is acting like a socially and politically engaged human being. By acting, the whistle-blower opens up space for other perspectives and discussion. To do this – acting – in the right way means that the whistle-blower should organize a support group right from the start. This support group facilitates the collection of different perspectives and keeps the focus on the situation; not just on the feelings and opinions of the fraudster, whistle-blower and friends. Using the Cynefin Framework supports the trajectory from 'not knowing where to begin' (disorder) to analyze the situation and respond accordingly to the complexity



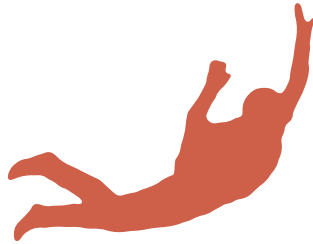
of the issue. Just like any other model or framework the Cynefin Framework offers only basic handles. When confronted with suspected healthcare fraud, the main lessons are: create a support group; collect different perspectives; realize that the views of the whistle-blower are just one perspective; focus on the given situation rather than the emotions of the persons in question; divide the situation into its component parts and place them in one or other of the domains; then respond according to the decision model belonging to this domain.

Doing the right thing (acting) and doing things right (avoiding pitfalls/using the Cynefin Framework) still do not guarantee a happy ending. Doing the right thing in the case of revealing healthcare fraud and doing things right will always be a path of painful uncertainty. The whistle-blower will always stay dependent on others. Is every relevant and involved person or institution willing to take action?

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# Chapter 10

It is all about the family.  
Mixed–method research on families  
with multiple and complex problems

Smit EH. It's all about the Family:  
Research on Dutch Families with Multiple and Complex Problems.  
Canadian Journal of Family and Youth / Le Journal Canadien de Famille et de la Jeunesse.  
2022;14(3):106–30.



## *Abstract*

Despite the scaling up of family-focused interventions, the number of child out-of-home placements continued to rise in the Netherlands. Most of these children came from families with multiple and complex problems. The underlying reasons for the rise of out-of-home placements were unknown. The main goal is to prevent children from being placed in out-of-home care. To achieve this, research was conducted to gain insight into the experiences of youth care professionals using family-focused interventions. A mixed method research study was done based on the questionnaire of Bodden and Decovic (2015). Qualitatively, 16 semi-structured interviews with youth care providers were conducted and a quantitative statistical analysis of 206 cases of families with multiple and complex problems were analyzed. Family-focused interventions are highly regarded and used by all stakeholders. However, help for families with multiple and complex problems is fragmented and so are the multiple (and possibly contradictory) family interventions. All 206 cases showed problems in all domains. Factors that interfere with family functioning are the most common, child factors the least. There is no significant relationship between child out-of-home placement and child factors. With each additional family problem, the chance of out-of-home placement increases by 10%. This study shows the complexity, not only of the families themselves but also the caregivers involved in these families. It is important to recognize and understand this complexity. Dealing with this complexity requires a different approach. The addition of a client supporter or an expert by experience is recommended.

**Key words:** Families, multiple problems, complex problems, outpatient treatment, family-focused interventions.

## *Introduction*

When a child is placed out of home there is a break in their development. The effects of multiple breaks on development negatively impacts development in adult life (Berger, Bruch, Johnson, James, & Rubin, 2009; Fantuzzo & Perlman, 2007; Mennen, Brensilver & Trickett, 2010). The Netherlands Youth Institute concludes in its report *Speerpunten voor residentiële jeugdhulp* (Spearheads for Residential Youth Care):

*Unintentionally, the system of youth care contributes to the negative spiral in which many children in residential youth care end up. Transfers, a lack of perspective, education that does not match their capabilities and under stimulation aggravate the problems they face (Netherlands Youth Institute, 2019, p. 5).*



Youth services in the eastern part of the Netherlands experienced problems in reducing the number of out-of-home placements and that out-of-home care often lasted longer than was expected. Family-focused interventions had been used to support families as much as possible, but results lagged behind. Most of the children who had been placed in out-of-home care came from families with multiple and complex problems (FMCP). Families with multiple and complex problems face a higher risk for developing more problems (Deković, 1999). Factors of influence are child factors, parent factors, childrearing factors, family functioning factors and contextual factors (Verhoeven, Junger, van Aken, Deković & van Aken, 2007). Bodden and Deković added two other factors: social network factors and mental health factors (Bodden & Deković, 2010). To gain a better understanding of the problems of families with multiple and complex problems and of the implementation of family-focused interventions in daily practice, the regional youth service initiated a study. The purpose of this study was to get tools to prevent or reduce the number of children in out-of-home placement. This required the involvement of mental health professionals and youth care workers working at local access facilities. The participation of parents was desired but unfortunately, due to the Corona Virus measures, could not be carried out sufficiently. The study was conducted by one principal researcher, the interviews were conducted by two researchers. A multidisciplinary sounding board was used to help decide on the research design and interpretation of the research results.

### *Research Questions*

- What experience do caregivers have with FMCP and with family-focused interventions?
- What problems do FMCP struggle with the most and is there a significant correlation between the different problems? How are these problems related to the (imminent) out-of-home placement of children?
- What potential means of improvements are there as a result of the research findings?

### *Method*

The research was based on a mixed method research process (Braun & Clarke, 2013). We started with a literature study in order to achieve a workable definition of families with multiple and complex problems. Subsequently, through an iterative process with the sounding board and the researchers, three research questions were drafted. A research

design was developed, including an interview protocol a pseudonymization protocol (with respect to the privacy of the families), and a communication plan.

Semi-structured interviews with youth care workers working at the local access centres and mental health providers (psychologists, psychiatrists) were part of the design, conducted by two researchers. These youth care workers are part of the local access teams and are part of the municipal youth service. Eleven local access teams were asked to participate in this study. Also 11 providers of youth mental healthcare and 2 youth protection organizations were asked to participate. In the end, 8 local access teams for youth care, 7 youth mental health providers and 1 youth protection organization participated in this research. This resulted in 16 semi-structured interviews with the following questions.

1. What is your perception of families with multiple and complex problems?
2. How many families are involved in your community, in your health-care organization?
3. What does the assistance to FMCP look like from your perspective?
4. What role do family-oriented interventions play in FMCP?
5. What are the advantages and disadvantages of family-oriented interventions in FMCP?
6. Where are opportunities to improve assistance to FMCP?

The interviews were conducted by two researchers (8 interviews each). The interviews were recorded – with permission – to support reporting. The reports of the interviews were summaries of the conversations while retaining concrete answers to the questions asked. Also, any examples that were seen as particularly significant were included verbatim in the report.

The interview consisted of three parts. The first part involved the open-ended question of, “What is your perception of FMCP” (question 1). The second part consisted of questions 2 to 6. This phase was concluded with the interviewees having the opportunity to add anything they felt had not been sufficiently addressed during this interview. After the third part, three FMCP cases were reviewed using the characteristics of FMCP developed by Bodden and Deković (2010). The interviewees could indicate whether or not the items mentioned were an issue, for example psychiatry or psychosocial problems including developmental problems in one or more children in this family. They could also name additional information if they wished. Additional information was for example “we are not sure, but have a strong suspicion”, or “we don’t know this information” or “we can’t say yet because the child is too young to conclude.” It was the interviewee who ultimately decided whether or not to tick the box. At the end of the

interviews, interviewees were asked if they would be willing to complete more FMCP questionnaires. Many did, resulting in 206 cases that were screened using Bodden and Deković's questionnaire. This data (206 scored questionnaires) was analyzed by SPSS. In the original design, it was also planned to link the pseudonymized cases to the data of the Region IJssel and Monitor (RIJM), a local dataset with information about the families and the giving care. However, the RIJM data proved to be unable to draw reliable conclusions for several reasons and after some consultation, this part of the research was therefore dropped. This research took place from January, 2020 to September, 2020. All interviews were conducted during the months of May–June–July and were conducted online due to the Corona Virus measures. An attempt was made to interview parents from families with multiple and complex problems as well. However, we did not find any parents willing to participate in this study.

## *Results*

With respect to the research question “What experiences with FMCP do youth care workers have with these families and with family-oriented interventions?”, the following results emerged.

### *The Interviews*

#### **General Picture of Families with Multiple and Complex Problems**

All involved were able to paint a clear picture of families with multiple and complex problems. Often mentioned were: multiple problems in multiple areas of life, low level of parenting, relationship problems, financial problems and high care costs. The psychological problems of parents were mentioned relatively more often than the psychological problems of the children. It was also frequently mentioned that the complexity and plurality can also be in the inability to find appropriate help. None of the interviewees worked with a standard screening list to distinguish when there is a family with multiple and complex problems.

#### **How many families are likely to be involved?**

None of the interviewees had a concrete overview of how many FMCP there are in their community. Families with multiple and complex problems are not specifically mentioned in reports as being FMCP. However, they did have some idea of how many families might be involved. The estimated number was related to the size of the municipality and/or the caseload with which they were familiar. A number of local access teams reported

that there had recently been a study into the top 10 most intensive and most expensive clients and their characteristics. Among this latter group are several FMCP.

**What does help look like for families with multiple and complex problems?**

The following help is provided (in no particular order): ACT team (intensive service delivery model intended for people with serious mental illness), Parenting support, Family treatment for children or babies with behavioural problems, CINGS (Child IN Healthy System), Basic Trust (treatment for children with problematic attachment), regular mental health care, domestic help, debt counselling, 10 for future (family counselling at home), Intensive Ambulatory Family Treatment, Intensive Psychiatric Family Treatment, Intensive Home Treatment, parent counselling, systemic therapy, trauma treatment, sexual problems treatment, broad-based counselling, 24-hour care, Cognitive Behaviour Treatment, Multidimensional Family Therapy, Non-violent Resistance and outpatient counselling.

The importance of parents taking charge of their own lives was widely recognized and endorsed. Examples of parents not taking charge of their own lives that were given were: complex divorces, psychiatric problems of one or both parents and families in which the parents did not agree with the solutions offered by youth care workers. It was indicated that families with multiple and complex problems in general are families who have difficulty in tapping into their own control. The reason given was that self-direction requires a specific competence that not everyone possesses.

It was indicated that the supply of help is fragmented, multiple parties contribute to the recovery of the individual child and/or family. As a result, families receive advice from multiple professionals and from different perspectives and with respect to different goals. There is collaboration but it is hampered by many changes of caregivers and seems to be mostly about “utility for one’s own responsibilities”. What do I need to know about the other person to be able to carry out my tasks and responsibilities well? Funding also made collaboration difficult. Access providers (bachelor degree), employed by the municipality, determine in the Netherlands whether specialized youth care professionals (master and PhD degree) may be deployed. Specialized youth care is provided by child psychologists and youth psychiatrists. When these access providers stop funding specialized mental health youth care for the (longer term) interest of the child, this complicates the mutual trust. Interviewees also mentioned that collaboration costs time and money. They indicated that they did not want to spend more time collaborating than actual helping the child and/or parents.

Whereas the specialized mental youth care providers seem to be looking more at what they can still offer, the access providers see the limited results of all the deployed care.

All recognized the pattern of stacking of help or continuous scaling up. A new provider offers hope and perspective and starts working adequately, until it no longer works and history repeats itself with the next provider. It was pointed out that this pattern does not stimulate the parents to take charge of their own lives. Choosing a new care provider that brings hope sounds like self-governance, but when disappointment follows, this then demotivates the self-governance.

A number of access providers mentioned the desire to work from broad and intensive deployment at the start and then to consistently scale down (instead of stacking and sealing up). The following image appeared:

- A proper screening at the start (when there are indications that this family might belong to the target group of multiple and complex problems).
- A concrete approach to the problems in several areas in which temporary taking over the direction is not shunned.
- Help that is aimed at normalizing the problems and reducing the complexity (not at solving and then preventing relapse).
- By adding an independent client-support person to this family, the encouragement of family self-direction can be sustained.
- Relapse prevention is found in sustainable, accessible and low-threshold support.

The question “When is the care good enough” came up regularly. As long as care providers do not have clear frameworks for this and families continue to ask for help, the two reinforce each other. Also, the question whether the help to FMCP should completely fall under the youth law was brought up several times. In the Netherlands the municipalities are responsible for making all forms of youth care available. For example, help at home with problems in the family, but also specialized mental youth care. Municipalities have a legal obligation to provide youth assistance and support. For example, to young people with a disability, disorder, disease or growing up problems. Reimbursing care to FMCP based on the youth care law, implemented by local municipalities, limits the latitude you have to be able to indicate help to parents only.

**To what extent do family interventions play a role in families with multiple and complex problems?**

Different family interventions are used (a wide variation, from well-defined methods to general interventions from the family perspective). Interviewees indicated that it is difficult to achieve results with parents who are unwilling or unable to do so. Enabling these families to use their own social networks is difficult to achieve. There is unanimous agreement that the focus should be at the family level and therefore everyone considers

the family-oriented approach of paramount importance. There is however hardly any harmonization at the family level with regard to the method of family interventions. The question that arises especially at the level of local access is where formal treatment ends and informal support begins and what is the place of support in the whole chain. The respondents indicated that there is no overview of which family-focused interventions are used when and by whom. The effectiveness of the multitude of interventions is especially questioned by the local access providers.

A number of those responsible for enabling local access mentioned that because family-focused interventions were only offered from the provider location; they lacked: "the eyes and ears in the family". According to them, family-focused interventions does not mean only listening, but also looking and feeling along, trying to get the family's perspective. When it comes to the effectiveness of family-focused interventions, they wonder what help is more appropriate: scientifically based family interventions at the location of the mental health providers or practical support tailored to the family. Youth care worker responsible for local access explains:

I went out to a family in a disordered household. I said, *'Let's do the dishes together.'* While the dishes were being washed, I would just talk to the mother or father about different issues.

When it comes to the expertise of the mental health providers, there is – even after additional training – a lot of hesitation regarding family-focused interventions. The importance of the working relationship between the psychologist and the parent(s) was often mentioned as a factor influencing the effects of the family-focused interventions. The psychologists sees the effects of the parent(s)' lack of competence in dealing with the children and at the same time sees the underlying traumas of the parent(s). Knowledge of family-focused interventions, of specific psychiatric behavioural patterns and/or factors of influence following a trauma and/or the practical hands-on help tailored to the individual are rarely held by one individual mental healthcare provider, so therefore, multiple mental health providers are deployed in the practice.

Less explicitly mentioned but frequently discussed was the desire for an integrated team that works on the basis of (a) an unambiguous vision and (b) an unequivocal methodology, (c) expertise in all areas, and (d) ample resources and (e) possibilities rather than problems. A team that focuses on reducing the multiple and complex problems in the family rather than a fragmented offering on sub-problems.

**What advantages and disadvantages to family–focused interventions in families with multiple and complex problems are mentioned?**

Although everyone is positive about family–focused interventions in general and considers their value indispensable, mainly points for improvement that were brought to attention with fragmentation mentioned most often. In no particular order, the following points were mentioned according family–focused interventions:

- A lot of fragmentation;
- You remain dependent on what the parents share with you;
- Implementation can be better, at the moment there is too much focus on the child;
- One family, one plan, does not work so well with this target group;
- Not every family–focused intervention empowers the parents;
- Social networks should be better involved;
- Family– focused interventions often work on the level of the problems in the family instead of on the level of the functioning of the family;
- We say we work family–focused, we think so, but do we really?
- Too little help is provided, there are too many partitions and not enough customization and flexibility;
- The waiting times for care are too long;
- There are too little intergenerational interventions;
- There is too much work on problems while there is not a solution for every problem;
- I miss a vision on normalization;
- After the family as a whole has been admitted to out–of–home, there is little targeted aftercare; the family then falls back;
- Too little attention to financial problems;
- In family–focused interventions, you have to be careful about your position as a psychologist;
- Starting with light interventions does not work sufficiently with these families;
- The psychiatrist has a lot of influence but does not see the family functioning in the home situation;
- It does not work well when specialist professionals starts saying what the generalist youth care workers should do;
- It is said that there is collaboration, but does this actually happen?

**Where are the opportunities for further development of family–focused interventions for families with multiple and complex problems?**

Concrete possibilities for development are mentioned, such as the use of a home support team, more room for creative solutions, increasing the expertise of the access team and the creation of a 0–100 team, up to more services with broad expertise in power of youth

probation and youth protection. Several interviewees indicated that the deployment of ACT teams would be a positive development, but that the criteria for deployment of this team creates (too) many obstacles making it difficult to access. Also, there is a need for more use of peer-workers, trained experts by experience and/or volunteers.

The wish for a development agenda also includes better practical handling of addiction problems, (structural) financial problems and complex divorces. The local access providers, and/or district teams indicated that they would like to have tools to better deploy their own network. They also wrestle with the question of how to keep out low-complex requests for help in a low-threshold environment.

A number of participants mentioned the need for more integrated care. But how do you get this done? And how do you cooperate more with each other and make the system of funding youth care less bureaucratic?

There is a need for practical guidelines regarding the normalization or de medicalization of psychological problems and for a manageable standard indicating to what extent family distress is acceptable. In other words: when is the care good enough? According to the interviewees, this desired development takes place at the level of (local) society.

### *The Questionnaire*

A total of 206 questionnaires were completed, of which 26 were done by mental health providers and 180 by local access providers and/or district teams.

The questionnaire multi-problem families of Bodden and Deković (2010) have seven domains, each domain has several factors. The seven domains are: child factors, parent factors, childrearing factors, family functioning factors, contextual factors, factors within the social network and mental health care factors. The question of the involvement of Safe at Home and/or the Child Protection Board was added in this study.



### Which areas or factors were most common?

To assess which areas occur most frequently, the scores per area are added up and divided by the number of questions. For example, family functioning (total score 889) contains six questions or factors that can be scored on:  $889:6=148.16$  rounded off to 148.

**Table 1. Most Mentioned Areas in the Bodden and Deković Questionnaire.**

Contextual factors such as multiple negative life events, financial hardship, and low Social Economic Status	151.6
Family functioning factors such as family conflicts, marital problems, and communication issues	148
Long history of mental health care, including out-of-home placement	124.5
Childrearing factors such as pedagogical powerlessness and attachment problems	120
Parent factors such as mental or psychosocial problems and cognitive problems	116
Involvement of Safe at Home and/or the Child Care and Protection Board–added question	114.5
Problems within the social network such as absent of social network	109.5
Child factors, such as psychiatric or psychosocial problems and cognitive problems	106

All cases had at least one positive score in each domain. The five most common factors were: multiple negative life events (93%), communication problems in the family (91%), psychiatric or psychosocial problems including psychosomatic factors in parent(s) (89%), psychiatric or psychosocial problems including developmental problems of (one of) the child(ren) (87%) and pedagogical powerlessness (87%).

If multiple negative life events were involved, 91% also included psychiatric or psychosocial problems of (one of) the parents, as well as communication problems in the family (91%) and psychiatric or psychosocial problems in (one of) the children (87%). If communication problems in the family occur, then in 93% of the cases multiple negative life events also occur, in 91% also psychiatric or psychosocial problems of parents, 87% psychiatric or psychosocial problems of the children, in 87% pedagogical

powerlessness and also 87% conflicts in the family occur. If psychiatric or psychosocial problems including psychosomatic factors are present in parent(s), 94% also have multiple negative life events, communication problems (93%), psychiatric or psychosocial problems in child(ren) in 88% and in 88% pedagogical powerlessness. If psychiatric or psychosocial problems including developmental problems of (one of) the child(ren) are involved, then 93% of these cases also involve multiple negative life events, 91% involve communication problems in the family and 90% involve psychiatric or psychosocial problems including psychosomatic factors in the parent(s). If there is a question of pedagogical powerlessness, then in 92% of those cases there are also several negative life events, in 91% communication problems in the family and in 90% there are also psychiatric or psychosocial problems including psychosomatic factors with parent(s).

In 10% of the cases there were 29 to 34 factors involved. In all these cases we see a parent with psychiatric or psychosocial problems, a parent who is or has been a victim / witness / preparator of abuse, inadequate parenting strategy, marital problems and multiple negative life events.

### **Families with Multiple and Complex Problems: Child, Rearing or Context**

The focus was on whether and with what other factors the child factors are related. This was due to the fact that all care of families with multiple and complex problems had been reported primarily under the name of the child while they were relatively less common than – as indicated earlier – family factors.

### **Child Factors**

In the domain child factors, 8 factors can be distinguished: 1) psychiatric or psychosocial problems including developmental problems; 2) behavioural problems; 3) psychosomatic problems and addictions; 4) cognitive problems (such as low IQ and learning disabilities) and intellectual disabilities; 5) victim or witness of maltreatment; 6) victim or witness of abuse; 7) neglect; and 8) victim or witness of domestic violence.

The child factors 'behavioural problems' and 'abuse' show no significant correlation with the problems within the other domains. There was a correlation, however, for the child factors 'psychiatric or psychosocial problems' (87%), 'psychosomatic problems' (28%) and 'cognitive problems' (51%) although they show significantly less coherence with other problems. Thus, the coherence they show is in a different direction than expected. This means that in those families where the child factor 'psychiatric or psychosocial problems' is present, there are significantly less often addiction problems of (one of) the parent(s) and low cohesion in the family. This means that in those families where 'psychosomatic problems and addiction child' are present, parents are less likely to be victims/witnesses/perpetrators of abuse and low socio-economic status is significantly

less likely. This means that in those families where 'cognitive problems of the child' are present there is significantly less often conflict in the family and significantly less often low cohesion in the family. There is a significant relationship with cognitive problems of the child with cognitive problems of the parent(s), but conflicts in the family play significantly less often.

In 48% of the cases, children witnessed or were victims of maltreatment. If children were victims or witnesses of maltreatment, there was a significant relationship with behaviour problems of the parent(s), addiction of the parent(s), are one or both parents victims, witnesses and/or perpetrators of maltreatment, with marital problems in the family, with conflicts in the family, with a lot of external locus of control, with lack of organization in the family, low economic status and conflicts with friends and/or neighbours.

In 54% of the cases, there was neglect of one or more children in the family. This neglect was significantly associated with behaviour problems of one of the parents, addiction of one of the parents, cognitive problems of one of the parents, with parents who are victims, witnesses and/or perpetrators of abuse, with lack of organization in the family, with financial problems, low social economic status (SES) and a disturbed or deficient social network.

**Table 2: How Victim or Witness Abuse is Related to Child Factors and Parenting Factors.**

Related variables	P-value	% with related problem in group with victim/witness of abuse	% with related problem in the group with no victim/witness of abuse	% with related problem in the whole sample
Parent: behaviour problems	<0.001	70%	36%	53%
Parent: addiction	0.001	37%	15%	25%
Parent: victim / witness / perpetrator of abuse	<0.001	97%	48%	68%
Family functioning: relationship problems	<0.001	90%	65%	76%
Family functioning: family conflicts	<0.001	93%	72%	82%
Family functioning: high external locus of control	0.037	71%	56%	61%

Related variables	P-value	% with related problem in group with victim/witness of abuse	% with related problem in the group with no victim/witness of abuse	% with related problem in the whole sample
Family functioning: no family organization	0.004	68%	47%	57%
Contextual: low SES	0.004	76%	56%	67%
Social network: conflicts neighbour's / friends	0.017	46%	29%	37%

In 54% of the cases there was neglect of one or more children in the family. This neglect was significantly associated with behavioural problems of one of the parents, addiction of one of the parents, cognitive problems of one of the parents, with parents who are victims, witnesses and/or perpetrators of abuse, with lack of organization in the family, with financial problems, low SES and a disrupted or deficient social network.

**Table 3: How Neglect is Related to Child Factors and Parenting Factors.**

Related variables	P-value	% with related problem in group with <u>with</u> victim/witness of abuse	% with related problem in the group with <u>no</u> victim/witness of abuse	%with related problem in the <u>whole</u> sample
Parent: behaviour problems	0.015	62%	44%	53%
Parent: addiction	0.049	31%	19%	25%
Parent: cognitive problems	0.001	59%	34%	46%
Parent: victim / witness / perpetrator of abuse	0.002	82%	61%	68%
Family functioning: high external locus of control	0.025	71%	55%	61%
Family functioning: no family organization	<0.001	70%	43%	57%
Contextual: financial problems	0.005	72%	52%	62%
Contextual: low SES	0.002	76%	55%	67%
Social network: disrupted social network	0.007	79%	61%	70%

Domestic violence was present in 54% of the cases, significantly correlated with 14 other factors.

**Table 4: How Domestic Violence is Related to Child Factors and Parenting Factors.**

Related variables	P-value	% with related problem in group with victim/witness of abuse	% with related problem in the group with no victim/witness of abuse	%with related problem in the whole sample
Parent: behaviour problems	<0.001	73%	28%	53%
Parent: addiction	0.003	34%	15%	25%
Parent: cognitive problems	0.018	55%	37%	46%
Parent: victim / witness / perpetrator of abuse	<0.001	96%	39%	68%
Family: relationship problems	<0.001	91%	60%	76%
Family: family conflicts	<0.001	97%	63%	82%
Family: communication problems	0.004	96%	84%	91%
Family: low cohesion	0.021	73%	57%	65%
Family: high external locus of control	0.004	73%	52%	61%
Family: no family organization	<0.001	69%	42%	57%
Contextual: financial problems	0.006	75%	55%	62%
Contextual: low SES	0.016	78%	60%	67%
Social network: disrupted social network	0.002	80%	59%	70%
Social network: conflicts neighbors or friends	0.006	46%	26%	37%

### Flawed or Disturbed Network

We zoomed in on the question of whether involving or helping the client's own network had a chance of succeeding. In the qualitative part (interviews) it became clear that involving the client's own network is very difficult. In 69% of the families, the social network is either inadequate or disrupted. In absolute terms this concerns 143 families (out of 206), 57 families were not affected and in six families it was not clear whether they had a deficient or disrupted social network. When it comes to the association between certain factors and a disrupted social network, we see a significant difference on several variables. The table below shows where the significant differences are between the group of FMCP with and without a disrupted and/or limited network.

**Table 5: Differences are Between the Group of FMCP with and without a Disrupted and/or Limited Network.**

Related variables	P-value	With disrupted network	Without disrupted network
Child: neglect	0.007	62%	40%
Child: domestic violence	0.002	64%	39%
Parent: psychiatric or psychosocial problems	0.035	93%	83%
Parent: cognitive problems	0.039	53%	36%
Parent: victim / witness / perpetrator of abuse	0.001	79%	55%
Childrearing: insufficient rearing skills	0.02	90%	77%
Childrearing: low parental responsiveness	0.015	60%	46%
Childrearing: attachment problems	<0.001	67%	35%
Family: relationship problems	0.014	82%	64%
Family: family conflicts	0.026	86%	72%
Family: high external locus of control	0.013	70%	50%
Family: no family organization	<0.001	70%	30%
Contextual: financial problems	0.002	70%	46%
Contextual: low SES	<0.001	75%	47%
Social network: conflicts neighbors or friends	<0.001	47%	19%
History with mental health care	0.008	89%	72%

### Relationship between Out-of-home Placements and Problems

We zoomed in on the relationship of the different domains and/or factors and out-of-home placement. The study shows that there is a significant relationship between the total number of problems in the family and 'risk of outplacement', 'involvement of Safe at Home' and 'involvement of the Child Care and Protection Board'. The chance of being placed in a home increases by 10% when one more problem is added to the family. The chance of involvement of the Child Care and Protection Board increases by 14% when one more problem occurs in a family. The chance of involvement of Safe at Home increases by 16% when there is one more problem in a family.

The tables below show which problems show significant differences between the groups where the factor 'long history with mental health care', 'out-of-home placement', 'involvement of Safe at Home' or 'involvement of the Child Care and Protection Board' is and is not present. We see for all three that there seems to be a connection with different problems in the family. What is particularly striking is that there is very little correlation between the removal of a child and the child factors. In addition, we see that 'involvement of Safe at Home' 'psychological problems child' and 'pedagogical powerlessness' show an unexpected opposite relationship (marked in green and with a \*).

### Long History with Mental Health Care

**Table 6: Differences between the Groups where the Factor Long History with Mental Health Care is and is not Present.**

Variable	P-value	With long history of mental health care	Without long history of mental health care
Child: cognitive problems	0.006	59%	31%
Parent: psychiatric of psychosocial problems	0.003	94%	74%
Parent: cognitive problems	0.044	52%	31%
Contextual: low SES	0.012	71%	47%
Social network: disrupted social network	0.008	76%	52%
Out-of-home placement	0.029	44%	22%

## Out-of-home Placement

**Table 7: Differences between the Groups where the Factor 'Out-of-home Placement' is and is not Present.**

Variable	P-value	Out-of-home placement	No out-of-home placement
Child: sexual abuse	0.008	16%	4%
Childrearing: low responsiveness	0.039	68%	53%
Childrearing: rejection	0.009	62%	42%
Social network: conflicts with neighbors or friends	0.016	49%	31%
Long history mental health care	0.029	91%	79%
Involvement Child Care and Protection Board	0.001	62%	38%

## Involvement Safe at Home

**Table 8: Differences between the Groups where the Factor Involvement of 'Safe at Home' is and is not Present.**

Variable	P-value	Safe at Home	No safe at Home
Child: psychiatric or psychosocial problems*	0.022	86%	97%
Child: victim or witness of abuse	<0.001	60%	25%
Child: domestic violence	<0.001	67%	36%
Parent: behaviour problems	<0.001	68%	27%
Parent: addiction	<0.001	34%	10%
Childrearing: parent is victim, witness of perpetrator of abuse	<0.001	82%	53%
Childrearing: low responsiveness	0.046	64%	35%
Childrearing: pedagogical powerlessness*	0.005	82%	97%
Family: conflicts	0.026	87%	73%
Family: relationship problems	0.006	83%	64%
Social network: disrupted social network	0.012	77%	59%
Social network: conflicts with neighbors or friends	0.004	47%	24%
Involvement Child Care and Protection Board	0.001	55%	30%



## Child Care and Protection Board Involvement

**Table 9: Differences between the Groups where the Factor Involvement of Child Care and Protection Board is and is not Present.**

Variable	P-value	Involvement with Child Protection Council	No involvement with Child Protection Council
Child: victim or witness of abuse	0.021	58%	41%
Child: domestic violence	0.013	67%	49%
Family: relationship problems	0.041	84%	71%
Family: high external locus of control	0.001	76%	53%
Social network: disrupted social network	0.016	64%	80%
Social network: conflicts with neighbours or friends	>0.001	56%	25%
Out-of-home placement	0.001	53%	29%
Safe at Home	0.001	79%	56%

### *Limitations to the Data Research*

There are a number of limitations in this study that may affect the results. This exploratory study focuses on families with multiple and complex problems where multiple significance tests were conducted. Due to the multiplicity of tests, there is also an increased capitalization on chance. Dichotomous data (concerning or not concerning) was used in completing the questionnaire. This did not sufficiently reveal the severity and extent of these problems. The percentage of applied cases (completed questionnaires) was 12% from the mental health providers (psychologists and psychiatrists) and 88% from the youth workers at the local access centres. This was mainly due to the willingness and/or ability to devote time to this. The perspective of local providers on FMCP is thereby more strongly represented than the perspective of mental health providers such as psychologists and psychiatrists.

The biggest omission is the lack of information from the families themselves. They are a hard-to-reach group and at the time of Corona Virus they had other priorities on their minds over participation in an abstract study. Also in the literature, only limited information is available on the perspective of family members from families with multiple and complex problems. We advocate other ways of reaching them, for example through expert by experience.

The 206 cases used for this research represent, in the best case, are only 1.0% of the total number of families with multiple and complex problems in this youth region (NJ, 2020, VNG, 2020). It is therefore recommendable to repeat this study in other youth regions to test the reliability of the results.

## *Conclusions*

This research started with three research questions. First, what experiences with FMCP do youth care workers have with these families and with family-oriented interventions? Second, what problems do FMCP face the most and is there a significant correlation between the different problems? How are these problems related to the (imminent) out-of-home placement of children? Third, what potential solutions become apparent from the results of the research?

### **What experiences with FMCP do youth care professionals have with these families and with family-oriented interventions?**

The image of families with multiple and complex problems that was presented by the respondents, corresponds to common descriptions in the literature. Multiple problems in multiple life areas, low level of parenting, relationship problems, financial problems, and high cost of care were most frequently mentioned. None of the respondents work with a standard screening list to distinguish whether or not a family has multiple and complex problems. None of the respondents had a concrete overview of how many FMCP there are. No link could be made between the registration system of the youth region and the insights of youth care workers regarding families with multiple and complex problems.

There is a broad support for family-focused interventions. At the family level, unfortunately, there is hardly any harmonization with regard to the method of family interventions. The supply of family-focused interventions is experienced as fragmented and a constant pile-up of help. Whereas the mental healthcare providers focus more on which scientifically substantiated interventions are possible, the local authorities seem to judge the effectiveness mainly on the structural results of the family-focused interventions.

The difficulty experienced by youth care workers in addressing the own social network of a family with multiple and complex problems is supported by the result that almost 70% of these families has a limited or disrupted network. The frequently mentioned hesitation to act and the cooperation problems between the different youth care providers / workers need to be further developed and improved.

All municipalities and also the youth region IJsseland in the east of the Netherlands have a vision on youth care, as a further elaboration of the Youth Act (RSJ, 2019). In practice, this vision falls short when it comes to handling families with multiple and complex problems. A low threshold and starting with small steps, one of the core elements on this vision, often leads to a continuous accumulation of care at FMCP which can have a negative effect on the self-reliance of the parents. Also, the question when the care is sufficient, good enough, could not be answered by professionals (alone).

**What problems do FMCP face the most and is there a significant correlation between the different problems? How are these problems related to the (imminent) out-of-home placement of children?**

At the domain level, we see that the domains of contextual factors – such as multiple negative life events, financial problems and having a low economic status – and family factors – such as conflicts, relationship problems and communication problems – are relatively more common than the domain of child factors while the child factors are often at the heart of youth care.

At the factor level we see that the top five most common factors are: multiple negative life events (93%), communication problems in the family (91%), psychiatric or psychosocial problems including psychosomatic factors in parent(s) (89%), psychiatric or psychosocial problems including developmental problems of (one of) the child(ren) (87%) and pedagogical powerlessness (87%). There are many different significant relationships between the factors. In 10% of the cases 29 to 34 (out of 37) factors were at play. In this 10% cases we see a parent with psychological problems, a parent who is or has been a victim/witness/perpetrator of abuse, insufficient parenting strategy, relationship problems and multiple negative life events.

A striking conclusion was that there was little correlation between the out-of-home placement of a child and a positive score on child factors. It could also be concluded that in those cases where there was involvement of Safe at Home, compared to the group where there was no involvement of Safe at Home, there were significantly fewer psychological problems of the child and the pedagogical powerlessness of the parents.

That there is a significant relationship between the total number of problems in the family with multiple and complex problems and 'chance of out-of-home placement', 'contact with Safe at Home' and 'contact with the Child Care and Protection Board' was partly to be expected. What was unexpected was the fact when one more problem in these families occurred, the probability of out-of-home placement increases with 10%. Also, if one or more new problems arose in these families, the probability of Child Care and Protection Board being deployed increases by 14% and the change of deploying

Safe at Home increases with 16%. This suggests that stabilizing and/or reducing the number of problems can reduce out-of-home placement and deployment of Child Care and Protection Board and/or Safe at Home.

Eighty percent of families with multiple and complex problems have between 14 and 29 (out of 37) defined problems. To give an idea of what such a family might look like, a case study below with 'only' 16 problems:

The Walters family consists of mother Ine, father Henrik and the children Emma, Luuk and Daan. Father and mother have (1) relationship problems which cause daily conflicts in the family; (2) Ine and Henrik both suffer from psychological problems; (3) whereby father, out of powerlessness, at times behaves aggressively; (4) there are financial problems; (5) these financial problems are not the first time; (6) because of all the tensions they no longer seem to understand each other well and the mutual communication almost invariably ends in quarrels; (7) this leads to a negative influence on their ability to use a consistent parenting strategy; (8) and their ability to respond adequately to the children; (9) Luuk and Daan show many behavioural problems; (10) with Luuk experimenting a lot with drugs lately; (11) Fortunately, Emma is very sweet and helps well with organizing everything the family needs to do; (12) Mother Ine loves her children very much but does not know how to manage her own problems and those of the children; (13) Ine and Henrik have hardly any contact with the family; (14) Ine's family hardly accepts Henrik. Henrik himself comes from a family with a lot of violence; (15) he has broken with them. For years, Ine and Henrik have been receiving help from an 'I don't know how many' care providers; (16) which requires a lot of organizational skills to keep track of all agreements and goals.

### **What potential solutions become apparent from the results of the research?**

The assumption that in families with multiple and complex problems, dysfunction as a family is the core problem, can be confirmed. The choice for more family-focused interventions thus seems logical and solving. However, these research results show that the solution (everyone offers family-focused interventions) simultaneously creates an additional problem when these family-focused interventions are insufficiently coordinated. To prevent fragmentation and further overburdening of the FMCP, the family-oriented interventions should be offered as an integrated supply. The youth region or municipality can stimulate this integrated care by considering integrated help as a necessary condition to be able to offer help and support to families with multiple and complex problems. It is understandable that the suffering of children is close to the heart of care workers and that respecting the autonomy of the family is highly valued in our society. Nevertheless, help should be primarily aimed at the functioning of the family as a whole, by ensuring a healthy(er) dynamic within the family for the

benefit of the child. The registration of families with multiple and complex problems also needs to be improved. When it comes to a FMCP registration and funding, this should be done at the family level. Reporting only at the child level gives a distorted picture of the costs in youth care. This means that there must be a better possibility of offering integrated care to children (Youth Act, implemented by the municipalities) and their parents (Health Insurance Act, implemented by health insurers). Using the characteristics of FMCP of Bodden and Deković, converted into a questionnaire, can be helpful in this regard. The final recommendation is to support families with multiple and complex problems with an independent client supporter and to make good use of experts by experience.

## *Discussion*

What this study shows is the complexity, not only of the families themselves but also the complexity of the caregivers involved in these families. It is important to recognize and understand this complexity.

Something is complex if its made up of usually several closely related connected parts, the more parts and the more connections are entwined within the system, the more complex it will be, and the more difficult it will be to analyze such a system (Sturmberg & Martin, 2013, p. 1).

Dealing with this complexity requires a different approach than usual (Ellis et al., 2017, Edgren & Bamard, 2012). To date, the tendency has been to address, for example, behavioural problems in children and/or limited parenting skills, with scientifically effective methods in order to reduce the number of out-of-home placements. This care was mostly provided by different health care providers from different organizations. In this context of increasingly specialized and cut up care, integrated care does not sufficiently develop (Rosenberg & Hickie, 2013). Flexible interactions between stakeholders is needed (Ellis et al., 2017). Relationshipbuilding and information sharing and space for self-organization is therefore required (Tsisis et al., 2012). So, one of the main challenges is the switch from solving disconnected problems to intervene in the dynamics of the family. Dealing with complexity, it is more effective to intervene with safe-trial-and-error interventions to more stabilize the dynamics of the family as a whole (Van der Merwe et al., 2019; Van Beurden et al., 2011; Snowden & Boone, 2007). We must however realize that this is easier said than done.

When a family has complex and multiple problems and there are several care institutions involved, it is advisable to use an independent client supporter or expert by

experience to support the family in its self-direction (Bakker et al., 2017). Independent client supporters or experts by experience are able to translate the wishes of the family into achievable goals and can act as a bridge to the care providers. They can contribute to improving the social network and can offer hope and perspective (Karbouniaris et al., 2020, Weerman, 2018).

By supporting the family as a whole, it may be possible to reduce the number of children placed out of home. And, in doing so, may be able to make a positive contribution to reducing the transformation of intergenerational dysfunction in families (Gomis-Pomares et al., 2021).

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# Chapter 11

De praktijk binnen de ggz is in ontwikkeling,  
volgt de wetenschap?

Smit, D., & van Os, J. (2022a). De praktijk binnen de ggz is in ontwikkeling,  
volgt de wetenschap? Tijdschrift voor psychiatrie, 692-695.



## *Achtergrond*

De combinatie van hoge prevalentie en sterke samenhang met de sociaal-economische status van psychische problematiek vraagt om een publieke vorm van ggz enerzijds en sterke samenwerking tussen ggz en het sociaal domein anderzijds. Met de brede omarming van herstelgerichtheid is tevens het besef gegroeid dat mentaal welbevinden niet los gezien kan worden van bijvoorbeeld zingeving, kwaliteit van leven en participatie. Pilots in de praktijk worden gestart om deze ontwikkeling integraal concreet vorm te geven. In hoeverre past het traditionele lineaire wetenschappelijke kader van specialistische diagnose-evidence-based symptoomreductie bij deze ontwikkeling?

## *Doel*

Stimuleren van de dialoog over de mate waarop het huidige wetenschappelijke paradigma van reductionisme en determinisme past bij domeinoverstijgende ontwikkelingen die binnen de ggz gaande zijn.

## *Methode*

Vanuit een wetenschapsfilosofisch perspectief op hoofdlijnen toetsen of het huidige wetenschappelijke paradigma past bij recente ontwikkelingen en beschrijven van een ander wetenschappelijk paradigma, de complexiteitswetenschappen. Als voorbeeldcasus beschrijven we het Ecosysteem Mentale Gezondheid (GEM).

## *Resultaten*

GEM sluit goed aan bij de complexiteitswetenschap, waarbij men de ggz benadert als een complex adaptief systeem. De concepten van emergentie en feedbackloops zijn ook nuttig om de dynamiek binnen GEM te begrijpen.

## *Conclusie*

Complexiteitswetenschappen bieden mogelijkheden om de huidige ontwikkelingen binnen de ggz te onderzoeken en te beschrijven. Dit vergt echter een gestalt switch in denken en een open houding naar nieuwe begrippen.

## *Inleiding*

In toenemende mate wordt erkend dat de geestelijke gezondheidszorg (ggz) toe is aan verandering. Afstemming tussen zorgvraag, –organisatie en –financiering zijn te complex en anomalieën worden gesignaleerd (Onderzoeksraad voor Veiligheid 2019; Algemene Rekenkamer 2020; Inspectie Volksgezondheid en Jeugd & NZA 2021).

De medicalisering van psychische klachten binnen de ggz (Whitaker 2005; Dehue 2008; Verhaeghe 2013) en de ‘identiteitscrisis’ van de psychiatrie (Gardner & Kleinman 2019; Braslow e.a. 2020) staan volop – en meer dan voorheen – ter discussie. Het uitsluitend conceptualiseren van geestelijke gezondheid in termen van stoornissen, slecht functionerende hersenen/cognitie, evidence-based richtlijnen en stoornisgerichte specialistische zorgpaden verliest steun (Delespaul e.a. 2016; van Os e.a. 2019). Mentale gezondheid kan niet meer losgezien worden van kwaliteit van leven, zingeving, meedoen in de samenleving en het dagelijkse functioneren en de behoefte aan zelfregie (Berwick 2016). De hoge prevalentie van psychisch lijden vraagt bovendien om een publieke aanpak naast de individuele (van Os 2018).

Ook op internationaal niveau is deze ontwikkeling zichtbaar. De Verenigde Naties waren uitgesproken in hun oproep aan psychiaters om de moed te hebben een ‘door crisis geteisterd en conceptueel verouderd systeem’ te hervormen (United Nations Human Rights Council 2017).

Wij durven te stellen dat de ‘gestalt switch’ in de ggz in feite al heeft plaatsgevonden. In het conceptuele project Redesigning Psychiatry van de TU Delft werd, in samenwerking met diverse zorginstellingen, gewerkt aan een nieuwe visie op de ggz met vier kernelementen: verhalen die men kan delen, patronen die doorbroken moeten worden, het verminderen van sociale druk en de noodzaak om te investeren in mentale vermogens (De Boer e.a. 2016). Scheepers (2020) benadrukt dat menselijk gedrag te complex, te dynamisch en te veranderlijk is om het binnen lineaire processen te kunnen vatten en ze pleit voor het loslaten van modellen. Een helder begrip van mentale ontwrichting is volgens Scheepers niet mogelijk, terwijl het denken in mentale modellen dit wel suggereert.

## *Beperkingen van het huidig paradigma*

In het huidige systeem wordt het persoonlijk verhaal van de cliënt en diens lijden vertaald naar symptomen, waarna de symptomen leiden tot een specifieke diagnose

van een psychiatrische stoornis. Elke psychiatrische stoornis heeft een beperkt aantal behandelmethodes waarbij de effectiviteit wetenschappelijk is aangetoond. De effectiviteit is met name vertaald naar symptoomreductie. Zo krijgt elke cliënt een diagnose en kan het succes van een behandeling deterministisch-re-reductionistisch worden voorspeld (Cassel 1982). Dit alles heeft geleid tot zorgstraten en/of specialistische teams waar kennis rondom één stoornis werd gebundeld met als doel meer efficiëntie en meer kennisontwikkeling. Hiervoor zijn hoogopgeleide zorgprofessionals nodig waarvoor veel financiële middelen nodig zijn en bovendien zijn ze beperkt beschikbaar op de arbeidsmarkt. Wanneer wij in staat zijn om psychisch lijden te zien als een vraagstuk met meerdere perspectieven, en waarbij de zelfregie van de cliënt een prominente rol krijgt, wordt zichtbaar dat we mentale gezondheid anders moeten gaan organiseren. Mentale gezondheid hangt onder andere samen met kwaliteit van leven, zingeving en participatie in de samenleving (Boevink 2017). Dit vraagt om domeinoverstijgende samenwerking en cocreatie; de ggz kan dit niet alleen. Het gaat ook niet alleen om persoonlijk herstel van de individuele cliënt, maar ook om herstel van de samenleving waar iedereen ambitieus, sociaal en succesvol lijkt te moeten zijn. Dit vraagt eveneens om ruimte voor emergentie, het adresseren van onvoorziene ontwikkelingen en het versterken van het adaptief vermogen op lokaal niveau.

### *Nieuw paradigma?*

De ontwikkelingen op het gebied van mentale gezondheid gaan in de richting van dynamische en zelflerende systemen, dwars door vormen van publieke, sociale en verzekerde zorg (Martin & Sturmberg 2012; van Spronsen & van Os 2021). De veranderingen gebeuren momenteel gelijktijdig en op verschillende niveaus: de overgang van het biopsychosociale model naar herstelgerichtheid (Boevink 2017) of het daaraan gerelateerde latere model van 'positieve gezondheid' (Huber e.a. 2011), van empowerment van de individuele burger met een psychische kwetsbaarheid tot aan de vervlechting van taken en verantwoordelijkheden van de ggz met het sociale domein en publieke domein (Nederlandse Vereniging voor Zelf-regie en Herstel (z.d.); van Spronsen & van Os 2021) en van de focus op de stijgende kosten naar meer clementie voor de kwetsbare groepen in de samenleving.

### *Hoe zou dat nieuwe paradigma eruit kunnen zien?*

De wetenschappers betrokken bij het Ecosysteem Mentale Gezondheid (GEM) gaan deze uitdaging aan. Zij oriënteren zich op wat de complexiteitswetenschappen te bieden hebben in een participatief en interdisciplinair open science framework. Complexi-

teitswetenschappen vormen het wetenschapsgebied gebaseerd op vijf intellectuele tradities die zich binnen de complexiteitswetenschappen deels coherent en gelijktijdig hebben ontwikkeld (Castellani & Gerrits 2021). Dit zijn dynamische systeemtheorie, systeemwetenschappen, theorie van complexe systemen, cybernetica en kunstmatige intelligentie. Vooral de concepten van 'complex adaptieve systemen', waarbij het aanpassingsvermogen van een systeem of organisatie belicht wordt, en het concept van 'emergentie' worden betrokken bij de wetenschappelijke onderbouwing van GEM. Emergentie is het resultaat van de interactie tussen verschillende elementen in een systeem, in dit geval de cocreatie (Sturmberg e.a. 2019), maar ook de interactie tussen sociale, publieke en verzekerde zorg (van Spronsen & van Os 2021). Het gezamenlijk opbouwen van een samenwerkingsrelatie en het ontwikkelen van een gedeeld inzicht en perspectief vragen om ruimte voor 'zelforganisatie' en professionele autonomie alsmede empowerment van de cliënt.

De GEM-hypothese is dat de zorg niet verbetert door de match tussen de hulpvraag en het bestaande aanbod binnen de ggz te optimaliseren, maar door gezamenlijk een antwoord te formuleren op de vraag van de patiënt. De variabelen die een rol spelen bij deze hulpvraag zijn divers. Het antwoord op deze hulpvraag dient dan ook gevonden te worden in een veel breder scala van mogelijke interventies dan nu wordt aangeboden (diversificatie). Dit vraagt om een verbreding van zinvolle en relevante interventies. In dit proces betreft GEM expliciet ervaringsdeskundigheid en/of peer support evenals interventies vanuit het sociaal domein alsmede het opkomende publieke domein in de vorm van e-communities (van Os 2018). Wat dit gaat betekenen, is het onderzoeken waard: wordt het aanbod zo divers en groeit dit exponentieel (positieve feedbackloop) of normaliseert deze laagdrempelige aanpak en vermindert de toestroom naar gespecialiseerde ggz (negatieve feedbackloop)?

Enkele voor deze ontwikkeling relevante begrippen uit de complexiteitswetenschappen zullen we kort toelichten. Dit zijn emergentie, complexe adaptieve systemen en feedbackloops.

## *Emergentie*

In een dynamisch systeem, zoals GEM, werken verschillende elementen op elkaar in om uiteindelijk door cocreatie een bepaalde synergie te vormen. In dit proces ontstaan 'bewegingen' die niet verklaard kunnen worden door de losse elementen. Dit wordt emergentie genoemd, beter bekend onder de uitspraak 'het geheel is meer dan de som der delen'. Emergentie is ons niet vreemd. In de behandelkamer gebeurt er meer tussen behandelaar en cliënt dan het delen van ervaring en het uitvoeren van handelingen.

Emergentie is, met andere woorden, het onvoorspelbare resultaat van de interactie tussen verschillende elementen in een systeem (Sturmborg e.a. 2019). Alhoewel emergentie niet afgedwongen kan worden, kan de waardering voor emergentie wel van betekenis zijn. Het biedt namelijk informatie over de wijze waarop een ecosysteem mentale gezondheid zich ontwikkelt en de ruimte die het systeem heeft om met deze emergentie om te gaan.

### *Complex adaptief systeem*

Een complex adaptief systeem (CAS) bestaat uit actieve actoren zoals patiënten, zorgprofessionals, managers, bestuurders, medewerkers van een zorgverzekeraar of overheidsinstantie, etc. Zij zijn onderling met elkaar verbonden, dwars door de domeinen van publieke, sociale en verzekerde zorg, zijn van elkaar afhankelijk en beïnvloeden elkaar waardoor het gedrag in de tijd evolueert (Ellis e.a. 2017). Een complex adaptief systeem bevat kenmerken om met deze complexiteit om te gaan, zoals adaptatie, zelforganisatie en samenwerking (Holland 1999; Sturmborg e.a. 2019; Ratnapalan & Lang 2020). Dit betekent dat wanneer men een complex adaptief systeem wetenschappelijk wil onderzoeken, dit niet kan door op lineaire wijze indicatoren te benoemen, te monitoren en te meten, maar dat je de dynamiek in dit samenspel van factoren probeert te vatten.

Wanneer we GEM als voorbeeld nemen, welke beweging zien we dan ontstaan wanneer lokale samenwerkingspartners de ruimte krijgen om zelforganiserend en zelflerend de mentale gezondheid te gaan verbeteren? Wat wordt dan uiteindelijk het equilibrium (het evenwicht) van dit lokaal ecosysteem? Met equilibrium wordt als het ware de comfortzone van het ecosysteem bedoeld. Op dit moment speelt de financiering van de geestelijke gezondheidszorg een dominante rol. De financiering wordt bepaald door behandelmethodes waarvan bewezen is dat ze effectief zijn en zo houden wetenschap en zorgverzekeraars elkaar in de tang. Is het mogelijk dat in de toekomst de mentale gezondheid en de daarmee samenhangende participatie in de samenleving van mensen met een psychische kwetsbaarheid in het centrum van het equilibrium komen te liggen?

### *Feedbackloops*

Het in kaart brengen van feedbackloops kunnen we zien als de tegenhanger van het bepalen en meten van indicatoren. Men onderzoekt welke factoren in de dynamiek elkaar remmen (negatieve feedbackloop) of elkaar verstevigen (positieve feedbackloop). Positieve feedbackloops versterken de output van het systeem, waardoor het systeem groeit. Negatieve feedbackloops temperen de output, waardoor het systeem stabiliseert rond



een equilibrium. Positieve feedbackloops zijn vaak nodig om de bestaande dynamiek te veranderen. Echter, wanneer er op een bepaald moment geen negatieve feedbackloops tegenover staan, kan de groei het systeem doen exploderen en/of uithollen. GEM stelt de mensen en hun behoefte aan zorg en ondersteuning niet alleen in de visie centraal, maar ook in het organiseren van mentale gezondheid. Om deze beweging op gang te krijgen zijn positieve feedbackloops nodig. Nadat de dynamiek in de gewenste mate is bereikt, dient men elementen toe te voegen om met een negatieve feedbackloop het ecosysteem in evenwicht te brengen.

Samengevat: om de mentale gezondheid te bevorderen, is een adaptief systeem nodig met een zekere ruimte voor cocreatie en zelforganisatie. Op basis van ontwikkelde feedbackloops wordt een veranderproces gestimuleerd. Om feedbackloops te ontwikkelen is inzicht nodig in de wederzijdse afhankelijkheid en onderlinge verbondenheid van alle betrokken factoren. Vanuit het paradigma van denken in complexiteit ligt de nadruk op het inzichtelijk maken van wederzijdse afhankelijkheid en onderlinge verbondenheid van alle belanghebbenden en op het ontwikkelen en monitoren van feedbackloops. De nadruk komt daarmee vooral te liggen op het verkrijgen van inzicht in de dynamiek in plaats van – zoals nu – op de resultaten.

## *Discussie*

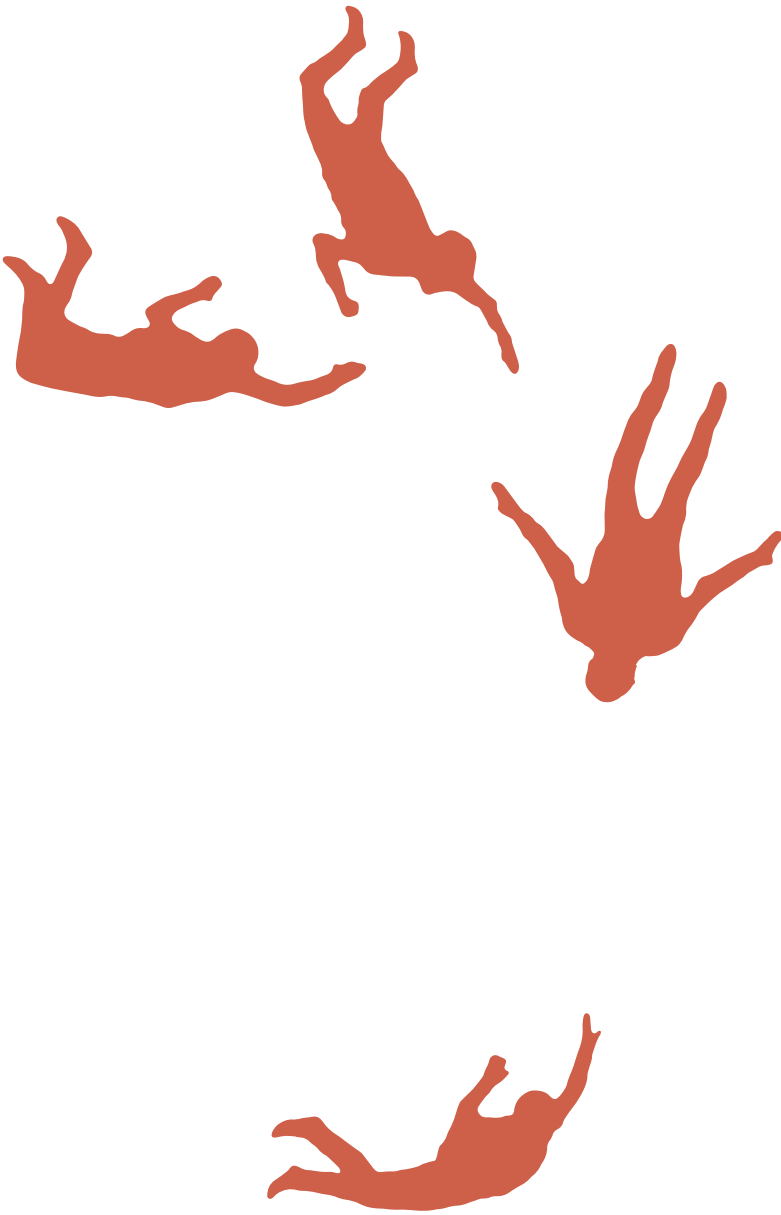
Het paradigma van complexiteitswetenschappen lijkt aan te sluiten bij de ontwikkelingen binnen de ggz waarbij er in toenemende mate domeinoverstijgend en in cocreatie gewerkt zal gaan worden, dwars door structuren van sociale, publieke en verzekerde zorg.

Naast de praktische pilots van het Ecosysteem Mentale Gezondheid van Van Os en Delespaul, maakt ook het theoretisch–conceptuele project Redesigning Psychiatry, van de TU Delft en een consortium aan ggz–instellingen, gebruik van concepten uit de complexiteitswetenschappen. Het zijn echter de eerste en voorzichtige stappen om te denken vanuit een ander wetenschappelijk paradigma. Het nadeel van de complexiteitswetenschappen is dat deze gepaard gaan met onderzoeksmethoden en een begrippenkader die weinig aansluiting vinden bij de begrippen van het huidige wetenschappelijk paradigma. Dit zou een flinke inspanning vragen van kenniscentra binnen de ggz.

Tot slot, zolang de financiering is gebaseerd op ‘weten is meten’ en de financiële positie van ggz–instellingen kwetsbaar is, zal er onvoldoende ruimte zijn om op wetenschappelijk niveau mee te bewegen. Ook als het gaat om de hervormingen van de ggz is cocreatie noodzakelijk.

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De overige literatuurverwijzingen zijn online te raadplegen



# Chapter 12

Het moet beter, het kan beter,  
maar gaan we het ook beter doen?

Smit, D., & van Os, J. (2022).

Het moet beter, het kan beter, maar gaan we het ook beter doen? GGZ Vaktijdschrift,  
2023;1(6):2–19, DOI: <https://doi.org/10.31739/GGZV.2023.1.2>



## *Samenvatting*

Het Integraal Zorgakkoord (IZA) benadrukt een aantal uitdagingen voor de ggz, zoals de medicalisering van psychisch lijden, gebrek aan ondersteuning voor mensen in een sociaaleconomisch kwetsbare positie en beperkte toegang tot zorg. Een integrale samenwerking tussen alle stakeholders wordt aanbevolen. De regie wordt gelegd bij ggz kerninstellingen. Dit roept de vraag op of de ggz kerninstellingen, met hun (hoog) gespecialiseerde kennis op basis van het biomedisch model, de meest voor de hand liggende aanjagers zijn van de veranderde focus op mentale gezondheid. Om deze vraag te beantwoorden is (i) een analyse gemaakt van feedback loops binnen de ggz, evenals (ii) een analyse van Vektis-data en CBS-data naar de relatie tussen sociaaleconomische data en ggz-kosten op PC4-niveau en factoren die daarop van invloed zijn en tot slot (iii) een analyse van een aantal aspecten van het IZA, met name de integrale samenwerking en de werkagenda samenwerking van de ggz met het sociaal domein en de huisartsenzorg. Hierbij wordt inzichtelijk welke patronen de huidige problemen binnen de sector in stand houden en waar de mogelijkheden liggen om het anders te gaan doen. De analyse suggereert dat een transformatie nodig is die voorziet in een andere manier van kijken naar psychisch lijden en een sterke waardengerichte samenwerking van partijen, dwars door wetten en settings, in een flexibel ecosysteem van sociale, publieke en medische hulpverlening.

**Sleutelwoorden:** Integraal Zorgakkoord, IZA, ggz, feedback, Vektis, CBS data.

## *Inleiding*

“Het moet beter, het kan beter, anders lopen we vast”, staat geschreven in hoofdstuk 1 van het Integraal Zorgakkoord (IZA) (1). Ondanks de wat negatieve formulering, zullen de meeste cliënten en hun naasten, professionals, financiers en bestuurders binnen de ggz dit statement kunnen onderschrijven. Ook voor “samen kunnen we de zorg toekomstbestendig maken” is een breed draagvlak te vinden. Waar de meningen nog over verdeeld zijn is de vraag hoe dat beter vorm dient te krijgen, onder welke voorwaarden, en hoe dat samen er in de praktijk uit zou moeten zien.

De focus van het IZA ligt op de zorg die onder de Zorgverzekeringswet valt, en werd in eerste instantie alleen door De Nederlandse GGZ ondertekend. Huisartsen hadden te weinig vertrouwen in het nakomen van gemaakte afspraken (2) maar hebben nadien alsnog getekend. MIND vindt dat de rechten van patiënten te veel onder druk komen te staan en heeft niet getekend (3).

In dit artikel wordt dieper ingegaan op de dynamiek van de huidige uitdagingen in de geestelijke gezondheidszorg. Daarbij worden feedback loops geanalyseerd en wordt de correlatie tussen psychisch lijden en sociale determinanten beschreven.

Hierbij wordt inzichtelijk welke patronen de huidige problemen binnen de sector in stand houden en waar de mogelijkheden liggen om het anders te gaan doen. Dit 'anders' ligt met name in een structurele aandacht voor de sociale determinanten die van invloed zijn op de mentale gezondheid. Vervolgens wordt dieper ingegaan op de vraag of er een overlap is tussen de zorg die ggz aanbieders bieden en de wijken of regio's waar op basis van de sociaaleconomische status meer mentale problemen verwacht wordt. Deze overlap blijkt beperkt. Daaropvolgend wordt ingezoomd op de werkafspraken vanuit het IZA. Adresseren de werkafspraken de uitdagingen in de ggz en waar liggen mogelijke verbeterpunten?

### *Feedback loops in de ggz*

“Niet alle vraagstukken vragen om een medisch antwoord. Het Nederlandse systeem rondom ondersteuning en zorg kent verschillende stelsels met verschillende vormen van bekostiging en een verschillend wetgevend kader. Dit zorgt voor versnippering van ondersteuning en zorg en leidt soms tot moeizame samenwerking tussen (zorg) aanbieders uit verschillende (zorg) sectoren. Om de maatschappij leefbaar te houden, en mensen waar nodig te ondersteunen bij hun sociale leven, gezondheid, participatie en omgang met hun gezondheid en kwetsbaarheid, is het essentieel dat er een goede verbinding is tussen de medische expertise (artsen), de verpleegkundige expertise (verzorgenden en verpleegkundigen) en de gemeentelijk sociale expertise (o.a. sociaal werkers en medewerkers publieke gezondheidszorg) en dat zij in staat worden gesteld om over de grenzen van weten en deelsystemen (waaronder de zorgverzekeringswet) samen te werken.” (1)

Mentale gezondheid wordt niet alleen gekenmerkt door bepaalde gedragspatronen. Er zijn op meerdere levensgebieden factoren die de mentale gezondheid beïnvloeden. Mentale gezondheid en de sociale determinanten zijn met elkaar verbonden en wederzijds afhankelijk van elkaar (4–9).

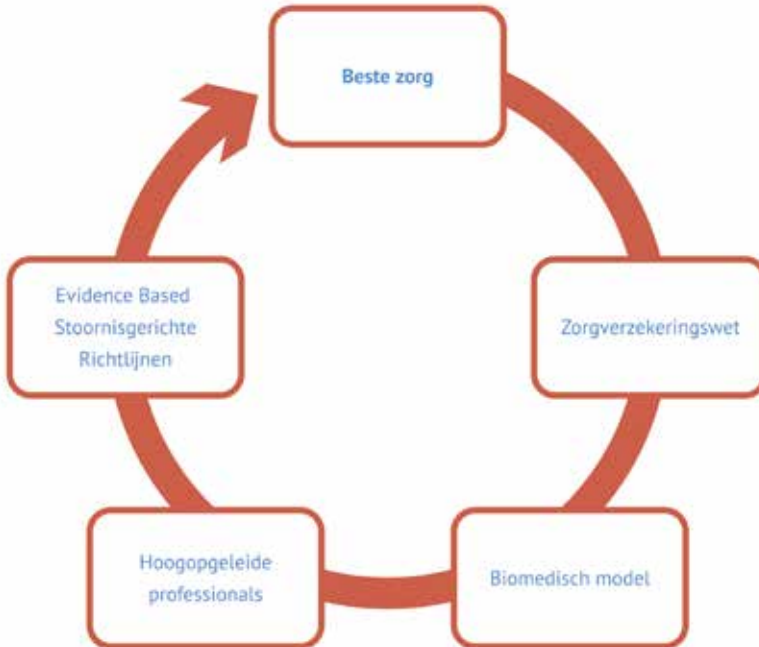
Sociaaleconomische omstandigheden beïnvloeden de mentale gezondheid en de mentale gezondheid heeft invloed op iemands sociale-economische omstandigheden (10). Sociale ongelijkheid hangt samen met het risico op psychische problemen: grotere ongelijkheid leidt tot een hoger risico op psychische problemen (11–13). Mensen met een laag inkomen hebben een hogere kans op psychisch lijden dan mensen met een

hoog inkomen (11–14). De levensverwachting van mensen met ernstig psychisch lijden is flink lager (15). Een onveilige jeugd en breuken in de ontwikkeling van een kind of jongeren geeft op latere leeftijd een hoger risico op psychische problemen (16, 17). Het verbeteren van de mentale gezondheid vraagt daarom om acties tijdens verschillende levensfasen en diverse levensomstandigheden. Bestaans(on)zekerheid is hierbij een belangrijke factor (18–20). Positieve gezondheid biedt handvatten om alle levensgebieden met elkaar in samenhang te bezien (21).

Wanneer er sprake is van een context waarin factoren van elkaar afhankelijk zijn en elkaar op veelal onbekende wijze wederzijds beïnvloeden, dan spreek je van een complex dynamisch systeem (22–25). Het lijkt erop dat we momenteel gevangen zitten in een aantal feedback loops, factoren die elkaar remmen (negatieve feedback loop) of elkaar juist versterken (positieve feedback loop). Feedback loops kunnen worden omschreven als een proces waarbij het effect terugleidt naar – of invloed heeft op – zijn eigen oorzaak (26–28). Neem de feedback loop van de beste zorg op de juiste plek als voorbeeld. Dit adagium wordt binnen de zorgverzekeringswet al jaren gepropageerd. Professionals die binnen de zorgverzekeringswet handelen, zijn allen hoogopgeleid. De hoogstopgeleide professional zorgt voor de beste zorg op basis van evidencebased richtlijnen en voor de beste zorg heb je een hoogopgeleide professional nodig (positieve feedback loop). Om ondanks deze positieve feedback loop de belevingswereld van de cliënt een betere positie te geven, is er in toenemende mate de inzet van ervaringsdeskundigen binnen de ggz mogelijk gemaakt. Wil je als ervaringsdeskundige binnen de ggz aan de slag om zo de beste zorg te kunnen leveren, dan moet je minimaal een hbo-opleiding hebben en voldoen aan het kwaliteitssysteem ervaringsdeskundigheid. Voor de beste zorg is ook een psychiatrische diagnose noodzakelijk, want zonder diagnose geen behandeling in de ggz (positieve feedback loop). Met andere woorden: niet de beste zorg. Zo lijkt de beste zorg als adagium gekoppeld aan de ggz, de ggz is gekoppeld aan de zorgverzekeringswet, de zorgverzekeringswet eist via de CONO-beroepentabel dat alleen hoogopgeleide zorgverleners de zorg mogen leveren en de hoogopgeleide zorgverleners werken als wetenschappelijk opgeleide zorgverleners op basis van wetenschappelijk 'bewezen' effectieve behandelmethodes zoals beschreven in de evidencebased richtlijnen binnen het biomedisch model. Deze feedback loop werkt als een attractor waar het lastig uit te komen is.



Figuur 1. Feedbackloop 'De beste zorg'.



Meer aandacht voor sociale determinanten van mentale gezondheid is in deze attractor niet eenvoudig vorm te geven. Psychische zorg en sociale zorg kennen in de praktijk helaas weinig samenhang (10). Zo kan het gebeuren dat hoogopgeleide welwillende professionals de beste behandeling bieden vanuit hun biomedisch concept van gedrag, maar nauwelijks de sociale determinanten adresseren. Ondanks dat deze sociale determinanten leiden tot een hogere kans op het in stand houden van mentale gezondheidsproblemen en bij het in stand houden van mentale gezondheidsproblemen de kans op behoefte aan ggz in stand blijft (positieve feedback loop). Kun je dan nog spreken van de beste zorg? In deze attractor is weinig ruimte voor zelforganisatie om het adaptief vermogen te voeden om de opwaartse druk van (te veel) positieve feedback loops te beperken (29).

### *Sociale determinanten en ggz aanbod*

Voor ggz aanbieders is het in de dagelijkse praktijk een bekend fenomeen: het effect van hun behandeling wordt beïnvloed door de ervaren armoede, eenzaamheid en/of sociale exclusie van hun cliënten. Hoe zit dat op een grotere schaal?

De ggz-dichtheid in Nederland is hoog: er zijn momenteel een kleine 10.000 ggz-aanbieders die jaarlijks meer dan 1 miljoen Nederlanders behandelen voor ongeveer 0.9% van het bruto binnenlands product (30). Ongeveer een derde van de regionale verschillen ggz-kosten, maar niet die van medisch-specialistische zorg of huisartsenzorg, is terug te voeren op sociaaleconomische verschillen tussen regio's (31, 32). Binnen de sociaaleconomische factoren met impact op het ggz-zorggebruik werd de grootste bijdrage geobserveerd voor een regionale sociaaleconomische score, onafhankelijk van geslacht, leeftijd, urbanisatie, regionale etnische dichtheid en kalenderjaar (31-33). De ggz in Nederland kent aldus een sterke sociaaleconomische gradiënt, met 25% tot 350% verschil in zowel zorgactiviteit als behandelprevalentie tussen de minst en meeste gedepriveerde PC4-gebieden.

Toenemende regionale sociaaleconomische deprivatie zou dus gepaard moeten gaan met een toename in complexe zorg ten opzichte van niet-complexe zorg, van klinische behandeling ten opzichte van ambulante behandeling, en van behandeling van ernstig psychische aandoeningen ten opzichte van minder ernstige problematiek (33). De relatief hoge mate van sociaaldemografische beïnvloeding of de 'verklaarbaarheid' van de ggz, is een belangrijk gegeven. Lagere sociaaldemografische verklaarbaarheid, bij gelijke regionale variatie, kan wijzen op andere bronnen van variatie, zoals variatie in aanbod. In Amsterdam en Rotterdam wonen bijvoorbeeld respectievelijk 817.000 en 624.000 mensen, of afgerond 5% en 4% van de Nederlandse populatie, maar de fractie van de landelijke zorgaanbieders voor traumabehandeling ([www.keuzeindeggz.nl](http://www.keuzeindeggz.nl)) in deze steden is respectievelijk 15% en 4%, en die voor depressie 12% en 3%. De jaarlijkse ambulante sggz-kosten per verzekerde voor depressie over de periode 2015-2018 waren 43 euro in Amsterdam en 33 euro in Rotterdam (cijfers per analyse dataset (33)). De verschillen in de kosten voor depressie gaan in tegen de sociale gradiënt (i.e. zijn niet sociaaleconomisch verklaarbaar), want het percentage hoogopgeleiden in Amsterdam is 48% (CBS, cijfers 2018) en 31% voor Rotterdam. Dergelijke verschillen tussen steden kunnen duiden op een aanbodgedreven gebruik van zorg (34), als ongewenst gevolg van de gereguleerde marktwerking die een aanbodgedreven patiëntselectie stimuleert uit de 20% jaarprevalentie van psychisch lijden (35). Wanneer we de sociale determinanten van mentale gezondheid serieus nemen is het zinvol om patronen van sociaaldemografische verklaarbaarheid van ggz-zorgkosten in Nederland te analyseren om de hypothese te onderzoeken dat ggz-zorgkosten variëren in de mate waarin ze voorspelbaar samenhangen met het sociaaleconomische populatieprofiel. Als dit zo is, zouden verschillen in proxy variabelen van verhoogd aanbod tussen regio's, bij gelijke mate van intra-regionale random variatie, gepaard moeten gaan met een lagere mate van sociaaldemografische verklaarbaarheid van de kosten, als beschreven in Figuur 1 op het niveau van de vier-cijferige postcode regio. Proxy variabelen van verhoogd aanbod waren de mate van stedelijkheid en de mate van hulpverleningsdichtheid.

## *Method*

In de Vektisdata werd een selectie gemaakt voor alle ggz-kosten die gemaakt werden door verzekerden van 18–65 jaar binnen de ggz voor de jaren 2015–2018. Hiervoor maakt Vektis gebruik van de declaraties die betrekking hebben op ggz, huisartsenzorg en de Wet langdurige zorg (Wlz). Deze kosten werden per jaar uitgesplitst naar de verschillende type zorg: poh–ggz, basis ggz (bggz), gespecialiseerde ggz (sggz), langdurige ggz (lggz) en ggz binnen de Wlz. De sggz werd verder onderverdeeld naar ambulant en klinisch en de verschillende diagnosegroepen. Per jaar werden de gemiddelde ggz kosten per verzekerde berekend. Hiervoor werden de ggz kosten (teller) verdeeld naar clusters van leeftijdsklasse (5 jaar), geslacht en PC4-gebied. De clusters van het aantal verzekerden (noemer) worden bepaald op basis van de verzekerdenkenmerken van alle verzekerden. Om herleidbaarheid naar personen te voorkomen werd de regel gehanteerd dat geen informatie werd gedeeld over een cluster waarbinnen het aantal verzekerden <10 is. Hierbij werd niet aangegeven op hoeveel patiënten de kosten per cluster en type zorg waren gebaseerd. Het is dus mogelijk dat de kosten voor een groep van 10 verzekerden onderliggend werden gemaakt door 1 verzekerde. Echter omdat deze kosten werden weergegeven voor alle 10 verzekerden samen, is niet herleidbaar welke individuele verzekerde(n) kosten hebben. Ook werd het aantal patiënten meegenomen, uitgesplitst naar jaar, postcode 4, leeftijdsklasse (drie klassen van 18–24, 25–64 en 65+) en geslacht. Indien het aantal patiënten kleiner was dan 10 werd het veld 'aantal patiënten' niet gevuld. De ggz-kosten voor de regressieanalyses waren de kosten per verzekerde. De kosten per unieke client (KPUC) werd berekend per PC4 gebied, jaar en leeftijd–geslachtscluster (3 leeftijdsklassen) als de ggz-kosten gedeeld door het aantal patiënten.

Gezondheidszorgkosten worden gekenmerkt door extreme waarden die resultaten kunnen verteken.

Kostenvariabelen werden daarom gewinsoriseerd waarbij de 1% extreme waarden per leeftijdsgroep en geslacht, alsmede per type zorg (bggz, sggz ambulant, sggz klinisch, poh, lggz, wlz) en diagnosegroep, uit de verdeling werden gehaald en vervangen door de waarde van het 99ste percentiel. De psychische hulpverleningsdichtheid werd bepaald door de som van alle werkzame personen die actief waren bij een instelling binnen 1 van de navolgende SBI codes: 86104 (geestelijke gezondheids- en verslavingszorg met overnachting), 86222 (Praktijken van psychiaters en dagbehandelcentra voor geestelijke gezondheids- en verslavingszorg), 86913 (praktijken van psychotherapeuten en psychologen), ingeschreven bij de kamer van koophandel over de periode 2015–2018.

## *Regressie-analyse*

De afhankelijke variabele in de regressiemodellen was ggz-zorgactiviteit, uitgedrukt als de gemiddelde kosten per verzekerde voor ieder leeftijd-geslachtscluster per PC4 gebied per jaar, met weging voor het aantal mensen per leeftijd-geslachtscluster in de analyses.

Kostwaarden ondergingen een zero-skewness logtransformatie met de Stata `lnskew0` procedure, werden gecentreerd en uitgedrukt in standaarddeviatie-eenheden (i.e. gedeeld door hun standaarddeviatie). Ggz-zorgkosten werden gemodelleerd in een regressie-model (Stata `regress` procedure) als een functie van factoren met bekende associaties met zorggebruik en ggz-zorgbehoeften (36–42), te weten: leeftijd (in jaren), geslacht, urbanisatiegraad (CBS 'macro' stedelijkheidsgraad op gemeenteniveau), kalenderjaar en een PC4-niveau sociaaleconomische index (uitgedrukt als een interval variabele met vijf niveaus van kwintielgroepen). Factoren gebruikt in eerdere analyses die niet bijdroegen aan het model werden niet geïncludeerd (31–32). De PC4 sociaaleconomische index was de geroteerde score van de eerste factor (35% variantie verklaard) van een factoranalyse van 48 demografische en sociaaleconomische PC4-niveau variabelen uit de CBS bestanden 'Kerncijfers Wijken en Buurten' over de jaren 2015–2018. Deze 48 variabelen betroffen de volgende demografische en sociaaleconomische dimensies: leeftijd, geslacht, etniciteit, inkomen, huwelijkse staat, geboorten, sterfte, woonverband, type woningen, wooneigenaarschap, leegstand, bouwjaar, huishouden inkomen, uitkeringen, type uitkering, bijstand, op/onder sociaal minimum, adresdichtheid, bevolkingsdichtheid, aantal inwoners. De eerste factor scoorde hoog op: jonge leeftijd, etnische minderheden, ongehuwd, 1-persoons huishouden, geen kinderen, meergezinswoning, huurwoning, woningcorporatiewoning, laag inkomen, op/onder sociaal minimum, bijstand en hoge adres- en bevolkingsdichtheid.

Toevoeging van tweede en/of hogere factoren uit de factoranalyse bracht geen verdere verbetering in kostmodellen en werden derhalve niet geïncludeerd in de huidige analyses. Gegeven de opbouw van de data van het aantal mensen in 18 leeftijd-geslachtsclusters in 4094 PC4 gebieden ontstaat een hiërarchische clustering in de data, te weten de leeftijdgeslacht groepen (niveau 1) die zijn geclusterd binnen PC4-gebieden (niveau 2). Correctie van standaardfouten voor clustering van de data op regioniveau werd uitgevoerd met de cluster optie in Stata.

## *Verklaarde variantie en ‘ggz-verklaarbaarheid’ parameter*

De determinatiecoëfficiënt  $R^2$  van het regressiemodel werd gebruikt als maat voor het deel van de variantie dat werd verklaard door het statistisch model. De  $R^2$  van drie modellen werd gebruikt om uit te rekenen hoeveel van de regionale verschillen in ggz-kosten werd verklaard door de fixed effects van sociaal-demografische factoren. In het eerste model werd het gedeelte van de variantie berekend dat kan worden toegeschreven aan alleen het random PC4-effect; dit was de  $R^2$  van het regressiemodel met de dummies van de PC4-indicatoren ( $R^2$ model1). In een tweede regressiemodel werd de  $R^2$  berekend van het model met alleen de sociaaleconomische factoren als boven beschreven ( $R^2$ model2). In het derde regressiemodel werd de  $R^2$  berekend van het model met zowel de dummies van PC4-indicatoren als de sociaaleconomische factoren ( $R^2$  model3). De berekening om te bepalen hoeveel van het regio random effect wordt verklaard door de sociaaleconomische factoren was als volgt:  $1 - [(R^2\text{model3} - R^2\text{model2}) / R^2\text{model1}]$  bepalen hoeveel van het regio random effect wordt verklaard door de sociaaleconomische factoren was als volgt:  $1 - [(R^2\text{model3} - R^2\text{model2}) / R^2\text{model1}]$ .

## *Geocodering resultaten*

Om verschillen tussen regio's aanschouwelijk te maken werd (i) de mate van variatie van kosten tussen PC4-gebieden (i.e. de determinatiecoëfficiënt van model 1) en (ii) de mate waarin PC4-gebonden variatie kan worden verklaard door sociaaleconomische factoren (i.e. de ggz-verklaarbaarheid parameter) met QGIS geocoderingsoftware geprojecteerd op de kaart van Nederland, geaggregeerd op gemeenteniveau en gewogen voor het aantal verzekerden, gebruik makend van vijf tinten rood voor de kwintielgroepen van deze variabelen.

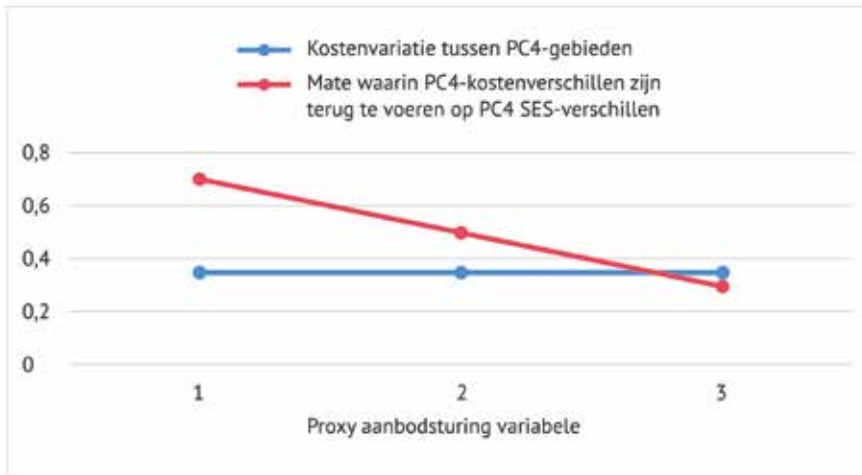
Proxy variabelen van aanbodsturing De volgende variabelen op PC4-niveau, gecategoriseerd op tertielgroep (met uitzondering van stedelijkheid), werden gebruikt als proxy-variabelen van aanbodsturing: stedelijkheid (3=G4 grote steden, 2=G40 middelgrote steden, 1 rest) en psychische hulpverleningsdichtheid (1=laagst, 3=hoogst). De gewogen correlatie tussen de twee variabelen was klein ( $r=0.15$ ). Om verschillende tussen de niveaus van de proxy aanbodsturing variabelen te interpreteren werden de kosten per verzekerde en de kosten per unieke patiënt berekend voor elk niveau van de variabele. Hogere kosten per verzekerde in combinatie met gelijke kosten per patiënt duiden op

verschillen in behandelprevalentie terwijl hogere kosten per verzekerde in combinatie met eveneens hogere kosten per patiënt ook duiden op intensievere behandeling.

### Grafische weergave resultaten

Resultaten werden weergegeven als afgebeeld in de hypothetische Figuur 2. Voor de verschillende categorieën van de proxy 'aanbodsturing' variabele, werd weergegeven de mate van kostenvariatie tussen PC4-gebieden alsmede de mate waarin deze kostenvariatie was terug te voeren op PC4-sociaaleconomische verschillen (de ggz-verklaarbaarheid parameter).

**Figuur 2.** Hypothetisch voorbeeld van de mate van kostenvariatie tussen PC4-gebieden (blauw) en de mate waarin deze PC4-kostenverschillen zijn terug te voeren op PC4 sociaaleconomische (SES-verschillen; rood), als een functie van een proxy 'aanbodsturing' variabele (x-as waarden 1 t/m 3).

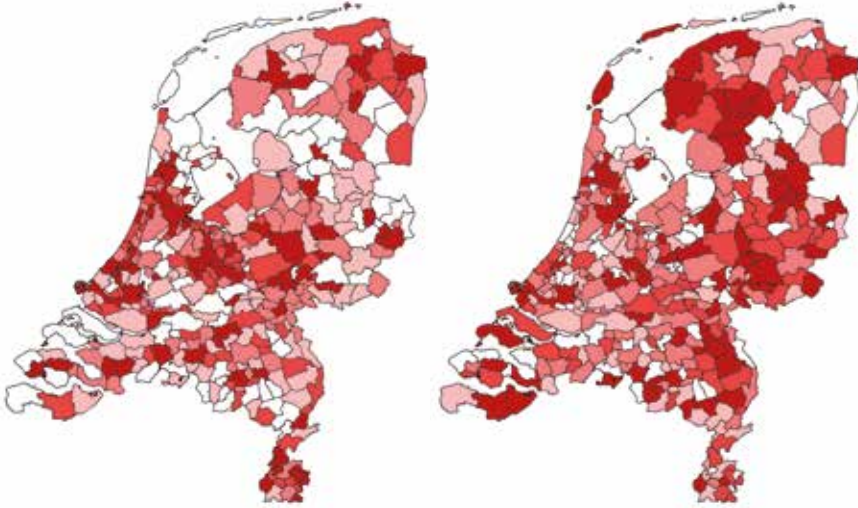


In de hypothetische figuur is te zien hoe voor de verschillende categorieën van de proxy 'aanbodsturing' variabele, bij gelijkblijvende kostenvariatie tussen PC4-gebieden, de mate waarin deze kostenvariatie is terug te voeren op PC4-sociaaleconomische verschillen, afneemt voor hogere waarden van de proxy variabele. De 'ggz-verklaarbaarheid' neemt dus af met hogere waarden van de proxy variabele, hetgeen kan duiden op een groter aandeel van het aanbod als verklarende factor van PC4-verschillen.

## Resultaten

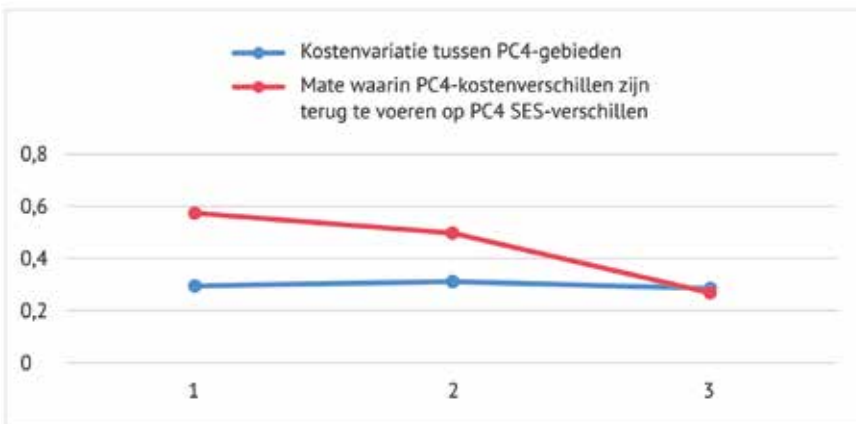
Geocodering van gemeenteniveau  $R^2$ model1,  $R^2$ model2 en de fractie van het PC4-random effect verklaard door sociaaleconomische factoren is afgebeeld in Figuur 2 en laat aanzienlijke variatie zien tussen regio's.

Figuur 3. Geocodering op gemeenteniveau van (i) mate van variatie van kosten tussen PC4-gebieden (links) en (ii) mate waarin PC4-gebonden variatie kan worden verklaard door sociaaleconomische factoren (rechts).

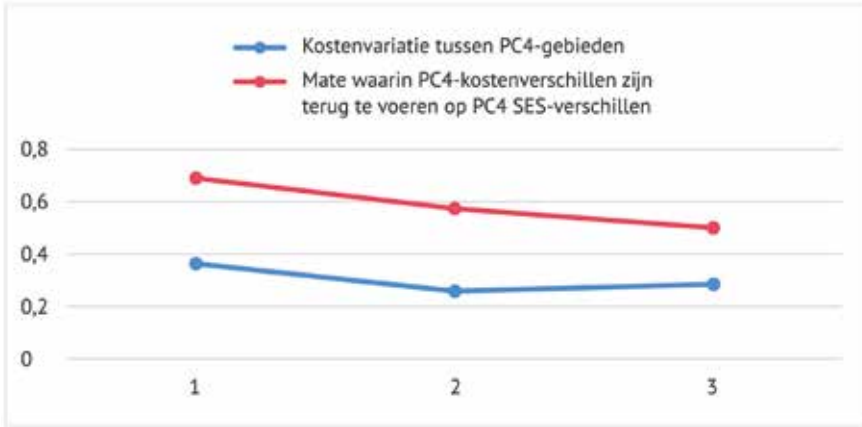


Figuur 4. PC4-variatie in ggz-kosten (blauw) in relatie tot de mate van sociaaleconomische verklaarbaarheid van PC4-variatie (rood), als een functie van proxy aanbodsturing variabelen.

Figuur 4a. Mate van Stedelijkheid (x-as; hoger = meer).



Figuur 4b. Ggz–hulpverleningsdichtheid (x–as; hoger = meer).



In Figuur 4 is te zien dat, voor elk van de proxy variabelen van aanbodsuring, hogere waarden van proxy aanbodsuring gepaard gaan met verminderde ggz–verklaarbaarheid door sociaaleconomische factoren, bij ongeveer gelijkblijvende PC4–gebonden variatie in kosten. Met name bij toenemende mate van stedelijkheid daalde de ggz–verklaarbaarheid parameter, maar ook bij hogere hulpverleningsdichtheid.<sup>5</sup>

Tabel 1 geeft weer de kosten per verzekerde, de kosten per unieke cliënt, de determinatiecoëfficiënten van de drie modellen en de ggz–verklaarbaarheid parameter, voor de drie niveaus van de proxy variabelen van aanbodsuring. Voor beide variabelen was de stijging in kosten per verzekerde sterker dan de kosten per unieke cliënt. Bij stedelijkheid was de stijging in kosten per unieke client niet lineair en zichtbaar met name als verschil tussen de laagste en de hoogste twee categorieën, terwijl bij hulpverleningsdichtheid de stijging in kosten per unieke client lineair was.

Tabel 1. Verklaarde variantie van ggz–kosten in verschillende modellen en de mate waarin PC4–verschillen in ggz–kosten worden verklaard door sociaaleconomische factoren, als functie van verschillende niveaus van proxy variabelen van aanbodsuring.

Proxy aanbodsuring variabele	Model	Kosten	Niveau <sup>1</sup>		
			1	2	3
Stedelijkheid		€ Kosten per verzekerde	234	336	369
		€ Kosten per unieke cliënt	2966	3267	3184
	R <sup>2</sup> model1		0.31	0.31	0.30
	R <sup>2</sup> model2		0.21	0.23	0.09
	R <sup>2</sup> model3		0.34	0.39	0.30
	GGZ verklaarbaarheid		0.58	0.50	0.28
GGZ Verlenings-dichtheid		€ Kosten per verzekerde	2084	262	318
		€ Kosten per unieke cliënt	2872	3034	3175
	R <sup>2</sup> model1		0.36	0.27	0.31
	R <sup>2</sup> model2		0.22	0.23	0.23
	R <sup>2</sup> model3		0.33	0.35	0.38
	GGZ verklaarbaarheid		0.68	0.58	0.50



## *Samenvatting*

In een analyse van de Nederlandse ggz–zorgactiviteit over de periode 2015–2018 werd sterke variatie gevonden in de mate van sociaaleconomische verklaarbaarheid van PC4–verschillen in ggz–kosten. De mate van sociaaleconomische verklaarbaarheid nam af met hogere waarden van variabelen die als hypothetische proxies dienden voor een hogere mate van aanbodgedreven ggz.

Zowel een hogere mate van stedelijkheid als een hogere ggz–hulpverleningsdichtheid, hoewel minder sterk, gingen gepaard met een lagere sociaaleconomische verklaarbaarheid van PC4–verschillen in ggz–kosten.

Bij de interpretatie van de bevindingen is de aard van de sociale gradiënt van ggz–activiteit van belang. Indien dit een causale invloed vertegenwoordigt is het valide om PC4 sociaaleconomische verschillen te behandelen als een indicator van de populatiezorgbehoefte waar de ggz aantoonbaar beïnvloed door zou moeten worden. Er is wetenschappelijk bewijs dat psychisch lijden, ongeacht de vorm, een sterk contextueel karakter heeft, vooral in relatie tot sociaaleconomische factoren (43). Sociale causatie speelt hierin een belangrijke rol, ook bij ernstige psychische aandoeningen (44–46). Het Nederlandse casus register en NEMESIS en NEMESIS–2 onderzoek heeft aangetoond dat sociale causatie een belangrijke rol speelt bij het ontstaan van psychopathologie (47–49). Ook als de sociale gradiënt een reflectie is van sociale selectie (prevalent psychisch lijden leidt tot neerwaartse sociale stratificatie) blijft het gebruik ervan als voorspeller van ggz–activiteit valide, omdat ook concentratie van psychische problematiek door selectie bijdraagt aan de ggz–zorgbehoefte van de populatie.

## *Integraal Zorgakkoord*

Het Integraal Zorgakkoord heeft betrekking op de somatische gezondheidszorg en de geestelijke gezondheidszorg en beperkt zich tot zorg die geboden wordt binnen de Zorgverzekeringswet. Het begrip integraal heeft hiermee een beperkte strekking. In hoofdstuk 1 “Inleiding Integraal Zorgakkoord, het moet en kan beter, anders lopen we vast”, wordt aandacht besteed aan de complexiteit van (mentale) gezondheid. Er wordt geschreven over de wens om patiënten de beste zorg te geven, die transparant en meetbaar moet zijn om ‘voor het toenemend aantal patiënten de beste zorg te kunnen (blijven) bieden met de beste kwaliteit en de toegankelijkheid te borgen door schaars personeel en dure infrastructuur optimaal in te zetten’ (1). Er wordt aangegeven dat niet alleen de zorg aan zet is, maar ook de politiek en de samenleving. De sociale

determinanten van mentale gezondheid worden onderschreven en er wordt benadrukt dat een medisch antwoord niet voldoende is (1). Bij de opgaven zoals geformuleerd in het IZA staan onder andere: waarborgen van een gelijke toegang tot zorg rekening houdend met diversiteit van de bevolking, inzetten van gezondheid en welzijn door middel van preventie en het verbeteren van uitkomsten van zorg door goed werkende digitale infrastructuren en bewezen innovaties. In onderdeel 'F' wordt verder ingegaan op de afspraken met betrekking tot het versterken van het sociaal domein en de sociale basis en het verbeteren van de samenwerking tussen het sociaal domein, huisartsenzorg en de ggz zorg. De gemaakte afspraken met betrekking tot het versterken van het sociaal domein en de sociale basis zijn onder andere dat a) de zelfregie centraal moet staan, b) er een landelijk dekkend netwerk van laagdrempelige steunpunten dient te komen zoals de zelfregiecentra/ herstelacademies met inloopfunctie, c) uitbreiding van het aantal digitale lotgenotengroepen (e-communities) en d) Welzijn op Recept dient opnieuw onder de aandacht gebracht te worden.

De meest concrete afspraak is het opzetten en uitrollen van Mentale Gezondheidscentra, die als sterke basis moet dienen om de veranderingen op gang te krijgen en wordt omschreven als essentieel om te komen tot aanvaardbare wachtlijsten. Binnen dit Mentale Gezondheidscentrum (dit is een werktitel, ook Ecosysteem Mentale Gezondheid (GEM) en netwerkpsychiatrie worden als voorbeeld genoemd) worden verkennende gesprekken gevoerd (50). De ggz kerninstellingen, leden van De Nederlandse GGZ, hebben een regiefunctie bij het vormgeven en het uitrollen van de Mentale Gezondheidscentra (p.72).

## *Analyse*

Op welke wijze adresseert het IZA de eerder beschreven ongewenste feedback loop van de claim van beste zorg (Figuur 1) en welke potentiële feedback loops zitten in de gemaakte afspraken?

### **De beste zorg**

Om toekomstbestendige medisch specialistische zorg te organiseren willen de partijen gezamenlijk de kwaliteit en continuïteit van de zorg voor de patiënt verder verbeteren, de transparantie daarover verhogen, het innoverend vermogen bevorderen en de samenwerking in netwerken in en tussen goed opgeleide teams waarborgen, zodat voor het toenemend aantal patiënten de beste zorg geboden blijft worden met de beste kwaliteit, doelmatigheid en doeltreffendheid. (1)p.51.

Het IZA bevestigt dat de beste zorg, zorg is die transparant en meetbaar is. Dit sluit naadloos aan bij de huidige geprotocolleerde zorg binnen de ggz maar staat ver weg

van ondersteuning voor de gevolgen van sociale determinanten die geboden wordt bijvoorbeeld vanuit een zelfregiecentrum/herstelacademie of e-community. Ondersteuning vanuit een zelfregiecentrum/herstelacademie of e-community biedt mensen ruimte om zelf te ontdekken wat hen helpt bij herstel en is lastiger meetbaar. Het transparant en meetbaar maken van dergelijke activiteiten kan, maar dan dient er gewerkt te worden op basis van een ander wetenschappelijk paradigma (9).

De beste zorg is zorg die transparant en meetbaar is en de indicatoren voor deze beste zorg vallen binnen de kaders van de Zorgverzekeringswet (en dus het biomedisch model) en wordt beoordeeld door hoogopgeleide professionals. Wat uiteindelijk de criteria worden voor deze beste zorg wordt vorm gegeven door het AKWA. AKWA GGZ staat voor 'alliantie kwaliteit in de geestelijke gezondheidszorg' en is een door 15 alliantiepartijen geïnitieerd kwaliteitsinstituut dat zich met name richt op ontwikkeling en onderhoud van kwaliteitsstandaarden binnen de ggz. Alle, op MIND na, zijn beroeps- of brancheorganisaties van hoogopgeleide zorgprofessionals binnen de kaders van het biomedisch model.

### **Sociale determinanten van psychisch lijden**

In de gemaakte afspraken wordt de feedback loop tussen sociale determinanten en psychisch lijden nauwelijks geadresseerd. Het verkennend gesprek, als onderdeel van de Mentale Gezondheidscentra, lijkt vooral te gaan om het versterken van de triage en daarmee het verkorten van de wachtlijsten. Het beeld wat op hoofdlijnen ontstaat is dat de Mentale Gezondheidscentra, opgezet door de huidige ggz kerninstellingen met hoogopgeleide ggz-professionals, verkennende gesprekken gaan voeren vanuit verschillende invalshoeken. Hoe deze ggz-professionals, opgeleid binnen het biomedisch model en weinig ervaring met de mogelijkheden van het sociaal domein, aan de verschillende invalshoeken komen, blijft onderbelicht. De aanwezigheid van bijvoorbeeld een ervaringsdeskundige bij een verkennend gesprek is niet verplicht.

GGZ Breburg heeft reeds ervaring opgedaan met het concept van Mentale Gezondheidscentrum en heeft haar ervaringen beschreven in het boek (51). Het verkennend gesprek nam per saldo 10% in beslag, 82% werd besteed aan intake en diagnostiek en behandeling en tot slot 8% aan MDO/Consultatie en preventie. De mogelijkheden tot consultatie en preventie (zoals ggz in de wijk) bestonden al langer, evenals de reguliere taken zoals intake, diagnostiek en behandeling. Is deze 10% verkennend gesprek voldoende om een kantelmoment te bewerkstelligen? De sociale determinanten komen er bekaaid af en blijven als luxerende factoren de positieve feedback loop aanjagen. Hoopvol is het versterken van het sociaal domein en de sociale basis. "Bij een hulpvraag kijken we naar de mogelijkheden van een ieder, waarbij de regie over het eigen leven centraal staat." P.70. Hiervoor worden zorg en welzijn op regionaal niveau meer met elkaar verbonden, voortgebouwd op bestaande werkstructuren. Er wordt een afspraak

gemaakt om in de komende vijf jaar te komen tot een landelijk netwerk van zelfregiecentra/herstelacademies en e–communities.

### **Gelijkwaardige samenwerking voor een gezonde dynamiek**

Het IZA versterkt de positie van de kerninstellingen van de ggz door bij hen de regie te leggen voor de gewenste veranderingen, al dan niet in samenwerking met andere partijen. Echter wanneer de oplossing ligt in een betere verdeling van het adresseren van zowel de mentale problemen als de sociale determinanten van mentale problemen, en de ggz juist zou moeten krimpen en de wijk- en e–communities moeten groeien, is het de vraag of een regiefunctie voor de ggz kerninstellingen in deze transitie voor de hand ligt. Wanneer gesteld wordt er meer gericht moet worden op gezondheid en minder op ziekte, dat de samenwerking tussen domeinen onder druk staat en er gekomen moet worden tot een andere verdeling van financiële middelen, dan lijkt een co–creatief proces waar alle stakeholders op gelijkwaardige wijze aan deelnemen daar meer recht aan doen.

In het IZA worden afspraken gemist hoe de mentale gezondheid bevorderd wordt door de sociale determinanten in evenwicht te brengen, bijvoorbeeld door een bepaalde bestaanszekerheid en sociale inclusie te garanderen. Het model van positieve gezondheid wordt twee keer genoemd, maar niet gerelateerd aan de correlatie tussen mentale problemen en haar sociale determinanten. De nadruk ligt nog sterk op goedopgeleide professionals, die overigens schaars zijn. Er zijn kansen gemist om de gelijkwaardigheid tussen ondersteuners en zorgverleners enerzijds en cliënten anderzijds te benoemen door te streven naar een situatie waarin ondersteuners en zorgverleners ook een afspiegeling zijn van de samenleving. Dit vraagt om meer inzet van ervaringsdeskundigen en hun naasten, meer openheid over de psychische kwetsbaarheid van ondersteuners en zorgverleners zelf en dit als kwaliteitscriteria op te nemen. Het woord 'onderzoek' komt meer dan 100 keer voor, het wetenschappelijk theoretisch kader voor dit onderzoek wordt echter niet toegelicht. Dit is wel cruciaal voor zowel de onderzoeksvraag, de onderzoeksmethode en de uitkomsten. De discussie over de vraag of de tweedeling tussen mentale en fysieke gezondheid nog wel toekomstbestendig is, wordt eveneens gemist.

## *Conclusies*

De beste zorg wordt geclaimd door de ggz binnen het kader van de Zorgverzekeringswet en werkt als een attractor voor mensen met psychische problemen. Met attractor wordt een situatie bedoeld waar een systeem zich naar toe ontwikkeld en zich in stand houdt ongeacht invloeden van buitenaf (52; 53). Hoewel er voldoende besef is dat mentale gezondheid samenhangt met sociale determinanten en deze daarom vanuit

meerdere perspectieven geadresseerd dient te worden, zijn de werkafspraken van het IZA wat eenzijdig. Het IZA lijkt zich vooral te richten op een verbeterde triage en het krimpen van de wachtlijsten. Het IZA geeft de ggz kerninstellingen een regiefunctie bij 'het moet beter en kan beter' terwijl uit onderzoek blijkt dat hun huidige clientpopulatie discrepantie vertoont met die regio's waar je op basis van sociale determinanten veel psychische problematiek zou kunnen verwachten. Meer zelfregie en persoonlijk herstel voor cliënten is nodig, het blijft echter de hoogopgeleide zorgprofessional met relatief weinig kennis van het sociaal domein, die beoordeelt welke zorg passend is. Meer laagdrempelige ondersteuning vanuit het sociaal domein is nodig, maar het zijn de ggz kerninstellingen die de regie voeren. De voorgestelde oplossing van het Mentale Gezondheidscentrum met een verkennend gesprek, zonder afspraken dat dit een multidisciplinair gesprek moet zijn, en visie over de verdere transformatie nodig is van de ggz zelf, biedt weinig hoop op verandering. Gelijkwaardige samenwerking en co-creatie met alle stakeholders (IZA ondertekend of niet) wordt gemist. De feedback loop die de toestroom in de ggz aanjaagt blijft bestaan.

## *Discussie*

Knelpunt blijft: wat is nodig om een persoon met psychisch lijden te voeden en te stimuleren om zelf te onderzoeken en te ervaren wat hem of haar zou kunnen helpen bij herstel? Hoe veranderen we de dynamiek dat professionals beoordelen wat voor de client het beste is, naar een integrale zorg op basis van een complex adaptief eco-systeem waarin mensen op de voor hén passende wijze aan hun mentale gezondheid kunnen werken (9)? Hoe stimuleren we een dynamiek waarin een persoon met psychisch lijden mag uitproberen wat het beste voor hem of haar werkt zonder het oordeel 'shoppen' er op te plakken en vooral te kijken naar de kosten? Hoe krijgen we het voor elkaar om domeinoverstijgend en vanuit een aangepaste financieringsstructuur de persoon met psychisch lijden daadwerkelijk in het hart van het Ecosysteem Mentale Gezondheid te krijgen? Hoe krijgen we de feedback loop van beste zorg naar een feedback loop op basis van haalbaar herstel – zoals weergegeven in Figuur 5 – waarin de sociale determinanten en integrale zorg en ondersteuning en een wetenschappelijk theoretisch kader op basis van complexiteitswetenschappen dit haalbaar herstel bevordert?

Figuur 5. Feedback Loop 'Haalbaar Herstel'.



Shim & Compton pleiten voor een gecombineerde aanpak tussen mentale gezondheid en publieke gezondheid (16). Een aanpak waarbij de stoornisgerichte, classificerende benadering van problemen wordt losgelaten en gestuurd zou moeten gaan worden op co-creatie met de verschillende domeinen waarbij aanbieders kunnen aantonen dat zij samenwerken en daarbij een zo goed mogelijke zorg leveren voor zo veel mogelijk mensen (54). Een aanpak waarbij de mens en diens persoonlijke herstelplan centraal staat in plaats van professionals die aangeven welke zorg zij op basis van wetenschappelijk onderzoek het meest passend vinden. Daarbij is het van belang dat de persoon met psychische klachten laagdrempelige toegang heeft tot ondersteuning, en dat hij/zij de weg weet en keuzes heeft om te komen tot passende zorg en ondersteuning (34–55–56). Wat gewenst is, is een situatie waarbij er niet alleen gefocust wordt op het verbeteren van de mentale gezondheid, maar naar een situatie waarbij er integrale aandacht is voor alle sociale determinanten van mentale gezondheid (10–57–58). Waar een stabilisering van de bestaanszekerheid leidt tot meer ruimte voor zelfontplooiing (59) en waar zelfontplooiing de kans op bestaanszekerheid vergroot (positieve feedback loop). Waar het optimaliseren van zelfregie/persoonlijk herstel leidt tot laagdrempelige herstelactiviteiten zonder medicalisering en laagdrempelige herstelactiviteiten zonder medicalisering leidt tot meer zelfregie/persoonlijk herstel (positieve feedback loop). Waar door structurele financiering van e-communities en zelfregie en herstelinitiatieven op basis van ervaringsdeskundigheid de noodzaak voor biomedische geestelijke

gezondheidszorg wordt verminderd waardoor, als gevolg van de verminderde kosten aan de biomedische geestelijke gezondheidszorg, meer financiële middelen voor structurele financiering aan e–communities en zelfregie en herstelinitiatieven op basis van ervaringsdeskundigheid (negatieve feedback loop) tot stand komen.

In het Integraal Zorgakkoord wordt de mogelijkheid van een adaptief bestuursysteem gemist. Een bestuursstelsel waarbij op basis van gelijke waarden en co–creatie gezamenlijk wordt gekomen tot regionaal passende zorg. Het besef dat een complex probleem een integrale aanpak op basis van gelijkwaardigheid nodig heeft waarbij er gebruik gemaakt kan worden van veel verschillende vormen van kennis en ervaring (60) komt slechts in beperkte mate terug in de oplossingsrichting van de gemaakte afspraken in het IZA.

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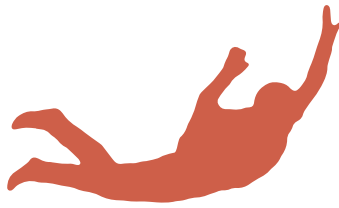
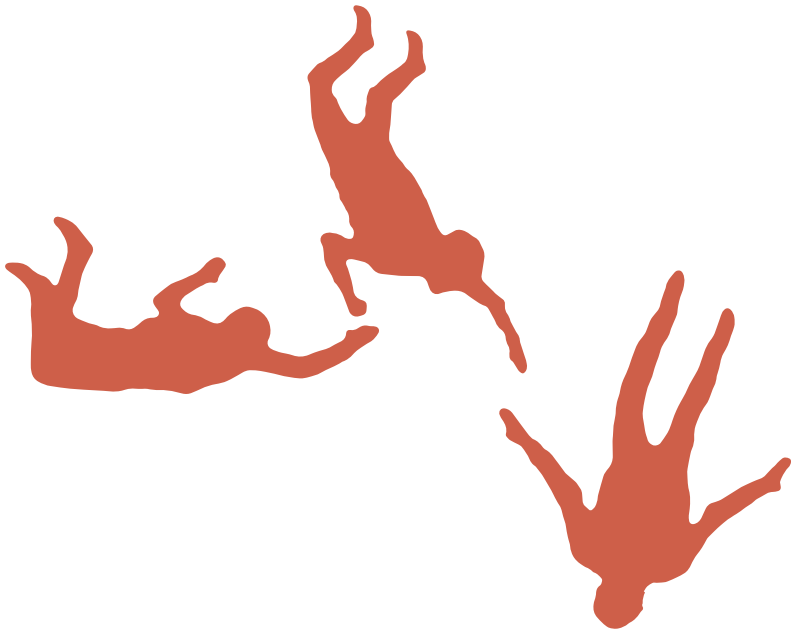


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# Chapter 13

Complexity of the Patient journey



## *Introduction*

The concept of 'patient journey' refers to the path that people with mental problems follow on their journey to recovery. The term patient journey is often used to describe a linear process in which goals and people, involved in the patient journey, are mapped out. But the term patient journey is more than just a useful tool. The concept of a patient journey also describes the complexity of different phases of recovery, different care providers and care systems involved, and the meaning for the patient of that journey (1). The patient journey gives insight into the different stages of illness and recovery, shows (the lack of) cohesion in the different parts of the care system and describes this from the perspective of the client (1).

## *The experienced complexity of the patient journey*

The complexity of the patient journey lies in the interconnectedness and interdependency of the personal circumstances of the person concerned. Mental well-being is connected to the quality of life, meaningfulness, social participation, daily functioning, and bodily functions (2, 3). Recovery is also finding your path through a scattered landscape within the mental healthcare and social services, within the formal and informal care and support. Recovery is hard work, finding your way to the different domains of recovery: clinical recovery, experiencing improvements in symptoms; existential recovery, having a sense of hope, empowerment, agency, and spiritual well-being; functional recovery, obtaining and maintaining valued societal roles and responsibilities, including employment, education, and stable housing; physical recovery, pursuing better health and a healthy lifestyle; and social recovery, experiencing enhanced and meaningful relationships and integration with family, friends, and the wider community (4, 5).

The importance of the working relationship during the patient journey is important but often underplayed. Norcross and Wampold label the working relationship as a common factor of all therapies (6, 7). According to Lambert (1992), 30% of common factors play a role in the treatment's effectiveness. A good working relationship is essential to bring about psychological change in a patient (8). The importance of the working relationship has also been repeatedly confirmed by several mega-studies (8–11). Bordin (12) identified three aspects of the working relationship: agreement on the goals of therapy, agreement on the tasks in therapy and the quality of the personal bond between patient and therapist.



The precondition for a good working relationship is equality. This means that patient feels free to say what is going on and that the information they provide is taken seriously (13). In 2016, the United Nations Educational, Scientific, and Cultural Organization found that there is too little attention to knowledge inequality. This lack of attention has implications for the sustainability of economies, societies, and communities (4, 15). Miranda Fricker identifies two forms of epistemic injustice, testimonial and hermeneutic (13). By testimonial injustice, Fricker means those situations in which someone has less credibility based on prejudice, for example, the perspective of the individual client with a borderline personality disorder is sometimes mistakenly viewed by professionals as 'behaviour explainable from the disorder' (16). The experiences of (former) clients are regularly undervalued (17). Hermeneutic injustice refers to the inequity when someone is not being heard sufficiently because they have difficulty putting words to what they want to express. There is a limited shared vocabulary. A good example is the word *depression*. In Dutch, almost everyone has an association with the word depression or depressive feelings. In Arabic however, the word depression does not exist. For people whose native language is Arabic, speaking about symptoms and mental disorders often requires more time and explanation. Not all people are used to having their 'heart on their sleeve' or are fully aware of the connection between their mental health, their lifestyle, the feasibility of their desires, their life circumstances, and their personal skills.

Within various cultures, God or Allah can play a role in discussing mental problems through a belief in evil spirits (18). It follows that the vocabulary of some groups of clients does not sufficiently match the regular vocabulary of most psychologists and psychiatrists. This can negatively affect equality and can lead to mutual distrust (19). Since the 80's there is a growing interest in the experience of (ex) clients with mental problems. In the beginning, their experiences were heard mainly through the client advisory councils. In the last few years, the role of the expert by experience has been gaining ground. The experts by experience are increasingly deployed within the mental health services (20). There are PhD studies in which the personal experiences as a client of the mental healthcare services have a prominent place (21–23). Hans van Eeken, an independent experience peer worker, has been working with these patients' journeys for quite a long time. Together with lector Bauke Koekkoek, he attempts to get the dialogue between the parties involved closer to each other (24).

Below are three (not previously published) patient journeys. They show some of the complexities they face during their journey to recovery. The question asked was: Can you tell me about your patient's journey? When did it start, what was the incentive and how did your journey proceed? Meet Eliza, Sarah and Noa.

**Eliza:**

Eliza experienced at age 22 a gang rape, involving boys she knew and who at the time were completely drunk. For one and a half years she tried to come to terms with this event. Until she finally cannot cope anymore, and drops out.

*“I couldn’t cope with school anymore, I broke down completely. I quit my study because I really couldn’t do it anymore. I didn’t dare to take the bus anymore, I had nightmares, I had flashbacks, I had voices that undermined me.”*

From that point on Eliza asked for help.

*“I went to a primary care psychologist. I didn’t say anything there about my voices, I didn’t say anything there about my trauma, they didn’t ask. There they diagnosed a chronic depression.”*

After some time, Eliza moves back to the hometown of her parents and comes into treatment with a psychiatrist. She attends several forms of therapy. During a group session, an incident happens and Eliza panics and dissociates to a severe degree.

*“Then a psychiatrist was called in, a psychiatrist in training, and then I came back, and then we talked about it. Then I said: I hear voices all the time and I started talking about voices and well, the psychiatrist in training called her supervisor, and then I was admitted to a ward for psychotic disorders.”*

The underlying trauma remained unaddressed.

*“Because of the stress, I couldn’t regulate my emotions. I was immediately put on medication. So everything was muted. I couldn’t deal with the tension properly, so I also started to headbang and strangulate a lot. I was not doing that because I wanted to die, but they saw it that way. So they saw it as a crisis and then I came to the crisis department in isolation. And yeah, as you can imagine in such isolation if they think you’re suicidal, which I wasn’t. Yes, and if then, if then you have to go into such an isolation room and your clothes are taken off... but if you’ve been through a gang rape... I flew at them and I was terrified to death! Really, really I thought really they are going to kill me. That lasted a very long time”*

*“I’ve also been on I think all the antipsychotics all kinds of antidepressants. I had a lot of side effects. It didn’t help against my voices either, antipsychotic at all. Yes, it numbed it, it, it knocked me out, but I had so many side effects. At one point I was*

*also diagnosed with schizoaffective disorder. I became very depressed, I understand, I thought I had no future prospects ”*

Treatment is being dominated by medication.

*“So I challenged even also up to court: guys, I don’t want this, this, this is not going well, I still have votes. This is not working. The stupid thing is that my lawyer, the confidant, the complaints officer, and so on said “well if they don’t get it now?! They must have really listened by now because you explain it well”. Yet the conclusion was always: coercive medication. At a certain moment, there was even talk of long-stay and then I really ended up in a depression and became suicidal. I made several suicide attempts, four of which almost succeeded. I’ve been in a coma for a few days. Then they said, oh, then you also have a personality disorder then suddenly borderline was set up. I had a total of twelve personality disorder tests and it always came out: you don’t have a personality disorder.”*

This phase lasted for years. Next, Eliza looks for and finds a place for sheltered living. While she and her family are setting up the room, she is told that the therapists consider her ‘too complex’ after all. The move is cancelled. At another institution for assisted living, the same thing happens. In the end, it is a personal assistant who gives the decisive answer and wants to give her a chance.

*“Then I was allowed to go there, after eight years of being an inpatient.”*

The care is considerate but also very protective. There is little support for her self-direction.

*“I need people to say, we have faith in you. For example, shopping. I didn’t dare to do so. I had been in the clinic for so long, that I had problems with a lot of stimuli. But instead of saying, go and do your shopping, we’re on call or something, we’ll help you... no, they took over. You were being kept very small while I was supposed to fly out but that is not what happened.”*

Eliza also got a new psychiatrist, the old pattern repeating itself. Contact with the psychiatrist was limited to crisis and medication. Until a tipping point took place!

*“At one point she [psychiatrist] said: we’re going to make an appointment, I want to talk to you. Huh?! What?! How can that be possible? How can it be? Because normally I only came to her when I was in crisis and suddenly she literally called*

*me, just on my phone and said: "we need to talk, I want to make an appointment with you". She then said I don't want this kind of relationship with you. This is not good for our treatment relationship. What do you want?"*

For the first time in over eight years a therapist, in this case, the psychiatrist, asked Eliza: What do you want?

*"And then I thought: what do you want? I got angry at first, I said yes, what do I want? I've been fighting for what I want for many years, no one even listened at all. What do you mean, what do you want? What do you want to achieve by asking? I was really angry! Then she said, I mean it, I really take you seriously, I just want to know what you want. So then I finally explained that I would prefer to live independently. I want to maybe do a study, maybe kids, a boyfriend, that is what I want. But I can't..."*

Then the psychiatrist asked why can't you?

*"And then I broke down... So then she literally pulled that cesspool loose. That was the first time I talked about my trauma to a healthcare professional. That was 12 years after it happened. And then she said: I don't think you have schizophrenia I think you should go to a trauma centre I think you have PTSD."*

*"Well, then I went to a trauma centre. Later I was signed up for the PIT STOP training. They signed me up for the AMBIT. There I was on the waiting list for a year and a half. Then they said I was getting another personality assessment. I say well, guys, fine, but then I was already half started. The AMBIT hit, so I thought a personality disorder not otherwise defined: fine. But it came out again: no personality disorder. Yes, then I had to stop again, so that was frustrating."*

Another five years after the moment the psychiatrist asked Eliza "what do you want?" Eliza lives independently, has followed training and is working as a volunteer.

**Sarah:**

Sarah experienced several traumas as a child, including years of sexual abuse by a family member. When she is 18 years old, she tells a friend about the abuse and how she struggles with it. Her friend advises her to contact the local youth care office.

*"The very first time I asked for help, it was really brief. At one point a friend of mine took me to the youth care office. At that time my struggles took up everything in my life. I was hugely confused by the abuse and how to relate to my family. All I knew was that I needed help. I had just turned 18 years old, so I knew the organization*

*wouldn't contact my parents without my permission. I got an intake interview and a few weeks later I received a written report. It said to look for a similar organization in my new hometown [ed. Sarah was going to study in another city a few months later]. For me, this was once but never again. Especially because I had to give a lot of details about my family, literal details about my parents, their names, date of birth, etc. All I felt was so much shame and I felt like a traitor to my family. I was so afraid my parents would find out. So it was once, but never again."*

Sarah goes off to study and she changes her study and residence a few times. And then it all went sideways.

*"In retrospect, I was very depressed at that time. I dropped out of college. I was hugely confused. I kept asking myself: Who am I? Everything felt very loose. I could no longer feel a connection. I was very depressed and suicidal. At some point, I started looking for help."*

Sarah continues her search for a compatible therapist.

*"I did several intake interviews. With one therapist I didn't click, another turned out to know my family, another became seriously ill shortly after starting the therapy, yet another soon got another job. Then I was referred to a psychiatrist, but after four times I left there. He wanted me to sign a non-suicidal contract. He said he didn't want to be held responsible if I jumped off a building. I couldn't promise him that. And in the meantime, more than a year had gone by."*

Eventually, Sarah finds a psychiatrist with whom it clicks. She goes to see her once a week for about a year. However, it does not bring her further in recovery. On the contrary. Sarah feels she is telling a lot, for the first time she is open about the abuse with a therapist, but she experiences little response. Her depression worsens and it is decided to admit her to a day treatment clinic for group treatment.

*"In the intake interview for the group treatment, I made it clear that the core of my problems had to do with the sexual abuse I had experienced as a child. During the treatment, the therapists focused on my depression, sleeping problems, alcohol and eating problems. The psychiatrist at the clinic specialized in ADHD and then concluded that all my problems could be explained by ADHD. I was given ADHD medication. During the therapy sessions, I tried to address things about the abuse, but the therapists didn't react to it. Nobody ever mentioned the abuse, even though I mentioned it explicitly in the intake interview."*

For Sarah, however, her traumas become more and more alive, resulting in more alcohol use and frequent self-mutilation.

*“I got even more depressed. At one point, I didn’t sleep anymore, despite heavy sleep medication. I became almost catatonic. For days I couldn’t speak, eat or sleep. As if my body had completely shut down. I was admitted to the crisis centre for two weeks. I was too scared to talk to the staff. But I thought they had read my file. That they knew I struggled with the sexual abuse. But in the end, it turned out that they had almost no preliminary information. They didn’t know anything about my personal background. They just gave me antidepressant medication. After two weeks I had to leave. I was given a choice: Admission for a longer period without treatment, or go home and take care of myself. I left and told them: I’ll do it myself. Even though I was still suicidal. I felt so let down.”*

Sarah decides to stop all treatment, including medication and starts with a new study. She also joins a running group, organized by the mental health institution where she was being treated before.

*“I was lucky that I ended up with this running group for young adult patients, which was led by a nice psychiatrist and a co-therapist. It was a small group and we ran twice a week in the park. I stayed with this group for two years. It gave me structure and prevented me from isolating myself further. And it was also just fun to do. Because of this psychiatrist, I started taking ADHD medication again which he prescribed.”*

After Sarah’s relationship breaks up, things go downhill with her again. The psychiatrist has never read her file until then and only talks to her about her ADHD symptoms. During this crisis, the psychiatrist asks follow-up questions for the first time. She tells him more about her struggles and the sexual abuse. He sends her in for diagnostic testing, suspecting complex PTSD. This is seven years after her first request for help.

*“He referred me for specialized trauma treatment, but there was a very long waiting list. I was able to join a stabilization course for women with complex PTSD instead. For this course, it was required that I also had individual therapy. They gave me the name of a sports therapist who also specialized in trauma. After six months of therapy, she said I was too intelligent and too complex for her. So then the treatment ended again.”*

Sarah continues to be treated for her ADHD – with yet another new psychiatrist. She learns more about her fears and the focus is mainly on learning to take better care

of herself. Her traumas are occasionally discussed, but not treated. After a year her therapist changes jobs.

*“After a while, I went to see my family doctor. I expressed that my life was still dominated by my traumas. And that each time during previous treatment I came to a point where I noticed: I have to start dealing with the abuse. The treatment as it is does not improve my quality of life.”*

Sarah is again referred to a trauma therapist. This one, unfortunately, becomes seriously ill and the treatment is temporarily taken over by a colleague in the same practice. This colleague isn't specialized in trauma. Sarah develops an attached relationship with this substitute therapist and she decides to stay with this therapist. She supports Sarah with her day-to-day problems and her study struggles. After one and a half years her therapist concludes that Sarah needs something else: intensive trauma therapy. She is referred to a specialized trauma centre for complex trauma / complex PTSD. Twelve years after her first request for help Sarah actually receives treatment for complex PTSD.

*“Finally I got intensive treatment where the main focus was my complex PTSD problems. Here all trauma treatment was evidence-based, so I received Exposure and EMDR treatment.*

After two years of treatment, there was an unexpected reorganization. I was told through the media that the trauma centre was going to be disbanded. It would end. There was tremendous unrest within the organization. It was kind of a crisis for me because I had become attached to the therapists. For me, it really takes a while to get there and I had finally entered into a therapeutic attachment because I finally felt safe. I had been satisfied with the therapists up to that point and I had benefited from the individual PMT and art therapy. The reorganization resulted in a therapy break of about nine months. The psychiatrist prescribed antipsychotic medication to get through this crisis.

*My psychotherapist went to work in the section of personality disorder care. Fortunately, I was able to stay in treatment with her. But the treatment shifted more and more toward 'schema therapy'. This was not so much due to the content of my treatment, but mainly due to a financial background within the organization. The complex trauma team disappeared from the organization and with it all the expertise.”*

Although the therapy makes sense in certain respects, it does not adequately address her request for help: to actually process her traumas. In all those years of intensive treatment, she learns a lot, but she does not make much progress regarding her trauma symptoms. The treatment regularly destabilizes her to such an extent that she has to

stop working. She is becoming more and more of a 'psychiatric patient'. She also goes through a very intensive hospitalization with exposure and EMDR treatment sessions. But these treatments do not work, which makes them even more traumatizing than helping her to recover.

*"I worked on my traumas for years, but it didn't work. More than anything, a lot more has come to the surface. But it didn't change anything. No, it disrupted me rather than helped me. I really became a patient. I ended up with much more psychiatric diagnoses than when I started the treatment. And in the end, they sort of gave up on me."*

By coincidence, Sarah's therapist is retiring and her treatment is taken over by a nurse specialist within a private practice.

*"It was a coincidence that I finally ended up with someone who takes a completely different approach. She does not work according to protocols. And she has tremendous expertise regarding complex trauma and dissociative disorders. She told me that she was shocked at how dissociative I was when I first came to her for treatment. She said to me: 'How is it possible that you've had so many years of intensive trauma therapy and still be so enormously dissociative? How is it possible that this was so missed in all your previous treatments?'"*

The nurse specialist has a direct and critical approach. She asks if Sarah wants to remain a psychiatric patient for the rest of her life. And she tells her that things can also be done differently. It turns out that a lot is still possible, now that her treatment is focused on Sarah's dissociative problems in combination with trauma recovery.

*"She said that a lot is still possible, and I found that very hard to believe after all those years. But actually, it turns out to be true!"*

**Noa:**

Noa comes from a family with multiple and complex problems.

*"My brother and I grew up in various forms of poverty. Because my mother insisted on moving, we moved six or seven times before I turned 18, and I changed schools three times before I went to secondary school.*

*We were in the WSPN [Debt Restructuring for Natural Persons Act] twice between the time I was a child and the time I turned 15.*



*The money problems were not over when I became an adult after my parents' divorce: I was financially exploited a few months before I started living on my own. Savings of 800 euros (I put my Wajong benefit aside every month): gone. I was put under pressure until I transferred the money.*

*My parents both have attachment problems, C-PTSS and autism. My brother, too."*

For generations, there has been abuse, mistreatment and neglect.

*"Let's see. There has been intergenerational abuse, mistreatment, neglect and ancestral trauma, passed down from one child to another, my parents have also been traumatised by that. That mark has come upon me and my brother as well.*

*They really don't understand that my brother and I are living beings, that we really are human beings, and that emotions are not strange at all. That their behaviour had consequences for us. I have seen and heard a lot of things happen. I have been very angry for a long time, very sad, and I have felt guilty towards my parents for a long time. I have also experienced a lot of disbelief and sadness because they both had to cope with years of abuse, mistreatment, and neglect. And even seemed to be one with this pattern. As it has happened to us, so it will have to happen to you."*

Noa sketches her mother's distorted view of life.

*"My mother actually did not want to marry and have children, she later told me, she never would have wanted my brother and me. I have had several death wishes thrown at me from a very young age. Her mood also fluctuated frequently and abruptly. I was praised before*

*I was verbally kicked to the curb. Partly for this reason, I find it difficult to accept compliments; I have developed a bit of an aversion to them.*

*I was brainwashed too, especially by my mother. That I would be sick. Partly because of that, I was often sick and was kept at home a lot. I went to many GPs, mainly because my mother thought it was necessary. Because of the many illnesses and absences, I had a learning disadvantage for two years at primary school.*

*I was also told that the world was an unsafe place and that everyone had bad intentions. That my father and mother were the only ones where I would be safe. Which wasn't true, but yes, I believed it anyway. As a result, I was a frightened child and I closed myself off from other people very much. I was bullied a lot at school."*

Her parents had a principle: as long as you live under our roof, we make the rules and you have no rights.

*“Am I actually allowed to set boundaries? My parents said you couldn’t, and I also thought so for a long time. They literally said that you can only set boundaries when you are over*

*18. Until then, we set the boundaries for you, because you live under our roof. You are our property, they both said. My parents had a strange view of reality. Until you were an adult, you were more of an object, and you could do whatever they wanted you to do, and that’s what they said. My parents had no boundaries. In retrospect, it probably wasn’t even unwillingness, but rather their incompetence.”*

Noa’s world stayed very small.

*“I liked to get lost in books. And especially about nature, books about animals, plants and fantasy creatures. And I also loved to draw and paint, because there was nothing else to do and I liked almost everything. I was not allowed to go outside on my own until I was 18 and otherwise never for long. Because my parents were afraid that I would run away and that people would know about the home situation.*

*From primary school onwards, I had to sit in the living room, and then I was often ‘interrogated’ by her for an hour or sometimes two. And then all sorts of things would be thrown at me that were not my responsibility.”*

Mental healthcare has been involved with the family since an early age. When Noa was 10 years old, she received her first diagnosis.

*“I was diagnosed with classic autism and a generalised anxiety disorder when I was ten. But I knew, this is not true. Because, I also had sleeping problems and nightmares that often woke me up screaming, but that had to do with something else. I was also stressed, very anxious and depressed and I was suicidal at a fairly young age. I also made a first attempt when I was very young . My brother pulled me off the road with a cycle step and all. This remained underexposed. My parents were the ones who were talked to, not with me. When I had grown up and had started to reduce my medication (at the urgent request of staff from adult psychiatry) and started to remember my story, my story was called into question. I still doubt parts of my story sometimes.*

*During my adolescence, staff in child and adolescent psychiatry said that they didn't think I had classic autism, but that it might be Asperger's and ADD. Then I said – I was 16 or 17 at the time – I said OK, I'd like a second opinion, I'd like a re-diagnosis. In the end, I went through a whole diagnosis process for nothing. My diagnosis remained classic autism and generalized anxiety disorder, at the most some basic data were updated. But at least that my IQ had risen slightly.”*

Noa is resisting the situation with limited means and possibilities.

*“I am the type of person who eventually resists. At a certain point, I was really done with the endless arguments and being afraid of my mother. I was done with her manipulative behaviour, mood swings, tiptoeing around her, being the lightning rod, lashing out at others and her projections. At a certain point, I wasn't afraid of her anymore, I was just fed up with it. Most of all, I just needed it to be over.”*

Noa is receiving counselling from youth psychiatry.

*“They did nothing but give me lots of medication for which I was resistant. I turned out to be therapy-resistant, pharmaceutical therapy that is. They didn't do any other treatment, except in the context of research. As part of that, I was given new medication and six weeks of psychomotor therapy. I have no idea what the results of that research were.”*

When Noa turns 18, she enters adult psychiatry.

*“I then came to other care institutions, one for adult psychiatry and the other for sheltered housing and outpatient counselling.*

*Unfortunately, my parents were treated by the same team, the autism team. So that was very unfortunate. It was there that I finally dared to tell my story on my own, but my story was questioned and I would have falsely accused my parents. Establishing a relationship of trust then became a lot more difficult. I eventually concealed some things and sometimes wore a fair-weather face.*

*Previously, my mother always insisted on coming with me to my meetings with the youth psychiatrist. Because my mother was afraid I would say certain things, for example about the home situation, there needed to be a degree of control. When I turned 18, that control disappeared overnight, because I was an adult.*

*It was very difficult to allow myself to be vulnerable and yes, I still find that difficult, to really allow all the emotions and feelings, if someone really wants to listen to me. Really standing still with my own story. Like: hey, this is what happened. I also notice that I find it difficult to tell it well: it is almost all at once and often a bit all mixed up, as I have told it a bit now. I'm trying to keep the line a bit now, haha.*

*Once, during a conversation with a case manager in adult psychiatry, I was told after I had finished talking about some of my traumas and the home situation: Are you sure that really happened? Do you know what you are saying? You can't talk about your parents like that. Those are very serious accusations that you're making. And I felt like... that hit me in the face!*

*She said I should have some respect for my parents and that they knew my parents very differently. I thought to myself: OK, so I won't talk about it anymore. Sadly, she was a very nice case manager who said this to me and I didn't confide in her about these things after that. Also because I knew that they would always reject my request for help based on some stigma about autism. My request for help was about mapping out my emotions and how I should best regulate them. In the end, they "gave me my way" because a baccalaureate student had to complete her training by doing an assignment: individual therapy. I would be a good training object. For six weeks, I was given the same exercise from a CBT workbook for young people under 18 with autism. I finally told her that I wanted to stop and wished her good luck with her study. A few months later, she called me to ask if I would still like to take up CBT with her because she had too few clients and could not complete her studies. I politely thanked her. I felt really bad for her, but I wouldn't have gained anything from it."*

Noa persists in living on her own. She could now find out for herself how to go about doing this.

*"It wasn't easy, because for years I didn't have access to things like a computer or a telephone. Eventually, I contacted two institutions. One was XXX and YYY, which was for people with intellectual disabilities. My mother had said that I would be mentally and multiple disabled and insisted that I should contact YYY first. I suspected that this was of little use, but decided to do it anyway. I gave my mother some feedback after that conversation with YYY. Her reaction was a bit tepid. "Oh, then XXX."*

*I had a conversation with someone from YYY. He came to visit my father and me. The care professional first wanted to speak to me in person; he soon realised that I was indeed not mentally handicapped. He did want to know how I came to be at YYY. I explained the reason why. I was very inhibited and told my story in a business-like*

*manner. I explained: well, this is where I came from and this is where I am now. I need a home as soon as possible, I have to leave the house, I am still in an unsafe home situation. Well, he saw that too, because I was not doing well. I had scars and healing wounds from self-harm, I was not able to express my emotions safely. I always felt very guilty when I did get angry with my parents or others I cared about, and then I cut myself."*

The care professional from YYY was understanding.

*"He said he was very angry about the situation and at my parents. He was glad I told him and thanked me for telling my story. He promised to take it away with my permission. He wished me good luck and that he hoped I would get on my way soon. He took a picture of me, he did this at all the house visits. As: "I won't forget you". That was symbolic for him."*

Eventually, Noa managed to get into a sheltered housing programme at XXX.

*"That was really a liberating experience, when I could be on my own, sort of, for the first time. Even though I lived with two other people in the same house. For the first time, I had my own room where the door no longer had to be left open. In fact, one of the first things I did – as soon as I was on my own – was to lock the door.. Wow, that was so liberating..."*

*No one could come into my room, things couldn't be moved or disappear, even the door to my bedroom could be locked from the inside. Do you know how wonderful? What a liberation!"*

Then there was room to deal with it...

*"Only... I didn't dare to leave my own house after that. Everything came out bit by bit. At a certain point, I was processing and reliving everything and I was just extremely tense and anxious and also sad. Everything had fallen away, even the contact with my brother. He was very much under the thumb of her [mother]. A whole mourning process had started. I closed myself off from the outside world again.*

*As soon as I went to live on my own, my brother wanted to see me less and less. At a certain point I had almost completely turned my back on my parents, and I visited them less and less often. A few years ago, he completely cut off all contact. At first, I really wanted to have contact with my brother, because he was the only person*

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*with whom I still had a good relationship. Now I don't anymore. It's not okay, but it's all right.*

*Meanwhile, I did want to make contact, even very much, but I was sometimes very susceptible to people who knew how to use or abuse me. I 'ran' after people and made myself very dependent. With my feelings of separation anxiety, I put friends and romantic partners at a distance."*

What is noticeable in Noa's patient journey is that she hardly ever talks about the therapy she received. When asked, she says:

*"Very little, actually. I was monitored and observed, but they didn't really listen to me. They mainly listened to what my parents had to say. No, I wasn't believed and I wasn't really taken seriously.*

*The things that especially my parents had indicated were written down in the dossier, were accepted and adopted unquestioningly by other care staff and, in fact, I was only given a pile of medication. People just didn't understand why I was getting all kinds of complaints like psychosis or psychosis sensitivity in any case. That my fears became more pronounced, that I was even more depressed, that I started perceiving things that weren't there, that at a certain point I was very suspicious, paranoid. They couldn't understand where all those complaints came from, because your mother said, your father said...*

*I have been in two special needs schools, one is a primary school and the other is a high school. At this primary school, I had the opportunity to overcome my learning disability. I spent two years there before I went to high school.*

*I liked and still like learning, especially when I can do something creative when I can work with my hands or with language, dance or music. I also liked the idea of a secondary vocational school, so that I could do an entrance course later (my parents did not want this). However, the teachers and my parents had a different views. Especially my mother did not want me to continue my education and find paid work. I met with the envy of my parents. It would have been like giving them the finger because they could no longer work.*

*In terms of support, I had a few teachers with whom I got on well. The remedial educationalist was very kind, but I had to watch what I said, otherwise I would have my parents on my back again. I didn't like that. In the end, I confided in one teacher*

*about the situation. She was very understanding of the situation I was in and kept her word not to do or say anything. I am still grateful to her for this.”*

Noa wants to move forward.

*“In the end, my former personal assistants within public mental healthcare – I’ve had two – thought I was too independent to be supported further towards studies and work and told me they only offered residential support. I would be smart enough to find my way in this. And I said: no, that is not true, because you also do a lot in the area of work and income and I would very much like to get an education. The specialist in mental health services gave me a similar answer to my request for help: you are smart enough so you can do it yourself. I told them I wanted more than medication, I wanted a good treatment program so I could deal with my emotions better and be more resilient in life. They said something along the lines of: if you think you’re so clever, pick up a book. I’ve read Pippi Longstocking books, so yeah... Let’s give it a try then, right?*

*I eventually followed that advice. Not just to be clever or stoic. I wanted to move on. I am indeed smart, but it’s not just what I need.*

*One was totally captivated by the recovery movement but missed a bit of the slogan I think. Yes, you do recover by yourself, but not all by yourself. The value of having a support network is now increasingly recognized. I just wonder what there is for people who don’t have a support system (anymore).”*

Noa has now been living on her own for several years without any support.

*The way I am in life now, I had never thought that I would ever be in this situation. I’m happy now and I’m stable.*

Noa will soon be attending vocational training with the hope of retaining her benefit and with the approval of the benefits agency during this training.

### *Summary and analysis*

It goes without saying that the patient journey of Eliza, Sarah and Noa has been tough and bumpy. Eliza suffers from negative voices but is also an intelligent young adult woman with a good education from a loving family. However, when Eliza tells she is hearing voices, she is admitted to the psychotic disorders ward and given a lot of

medication. When she reports that the medication has more negative side effects than positive effects, her opinion was ignored. The interconnectedness between hearing voices and the side effects of medication remains underexplored. She is not asked what she needs and what others could do for her, she receives – as you may assume – an ‘adequate’ treatment aimed at her symptoms: hearing voices. Sarah went through a long quest to (learn to) talk about her sexual abuse experience.

Due to different circumstances, she has had many different therapists, which contributes little to mutual trust. Her mental health problems are serious and she is willing to work on them. The interconnectedness between her experiences of sexual abuse and her psychological complaints remains underexposed. All treatments have little effect “But it didn’t change anything. No, it disrupted me rather than helped me” she said. In Noa’s case, the struggle for her existence seems to continue unabated, despite well-intentioned care and support. She experiences little recognition of the interconnectedness of what she has been through and her view on the world. Feelings of insecurity are hardly addressed. Sarah’s patient journey was primarily managed by mental health professionals. Sarah had only limited influence. She was offered a choice between two extremes that barely matched her request for help: admission for a longer period without treatment, or go home and take care of herself. Noa’s patient journey appears to be mainly about mutual trust. In contact with mental healthcare professionals, Noa’s longing to construct and have her story and personal experiences acknowledged without judgement, plays an important role. The working relationship as described by Borin – despite good intentions – hardly emerges.

From a Positive Health perspective, there seems to be a focus on treating the disorder and/or solving mental problems, rather than looking at the different domains of recovery. From an Epistemic Injustice perspective, it seems their request for help was not understood well or even ignored. From the perspective of the working relationship, there seems to be little agreement on the goals of therapy and agreement on the tasks in therapy. Eliza, Sarah and Noa found sporadically a pleasant personal bond between patient and therapist.

Viewed retrospectively, the stories of Eliza, Sarah and Noa suggest recovery from mental health problem is more complex than reducing symptoms of a mental disorder. A recovery-supportive dialogue could have saved much suffering. An (peer supported) open dialogue where personal circumstances are seen as interconnected with the challenges of life and the need for recovery could be of added value. A recovery-supportive dialogue in which the interlocutor is aware of the pitfalls of epistemic injustice and realizes that mental health is interconnected with functioning in and experiencing other areas of life. The aim could be to support the patient – without a predetermined framework – to

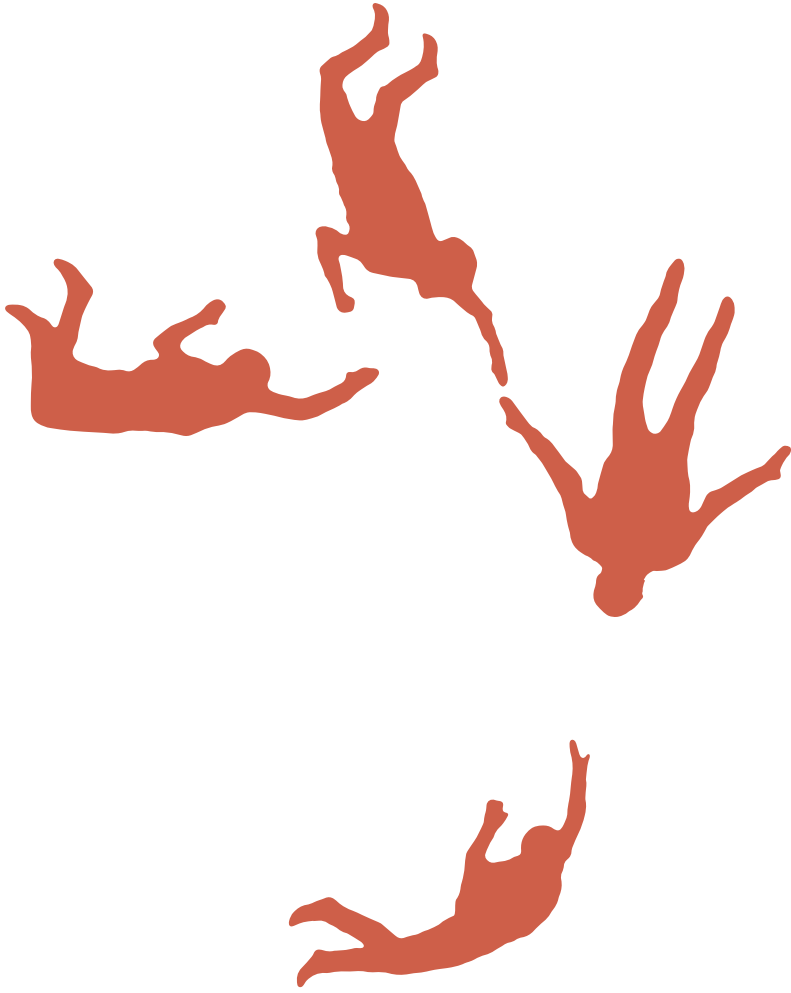


get a better understanding of the wishes for recovery. The result could be a recovery plan where the patient can make choices that are appropriate and feasible. Peer-to-peer support can be a valuable component in this.

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# **PART III**

## **Chapter 14**

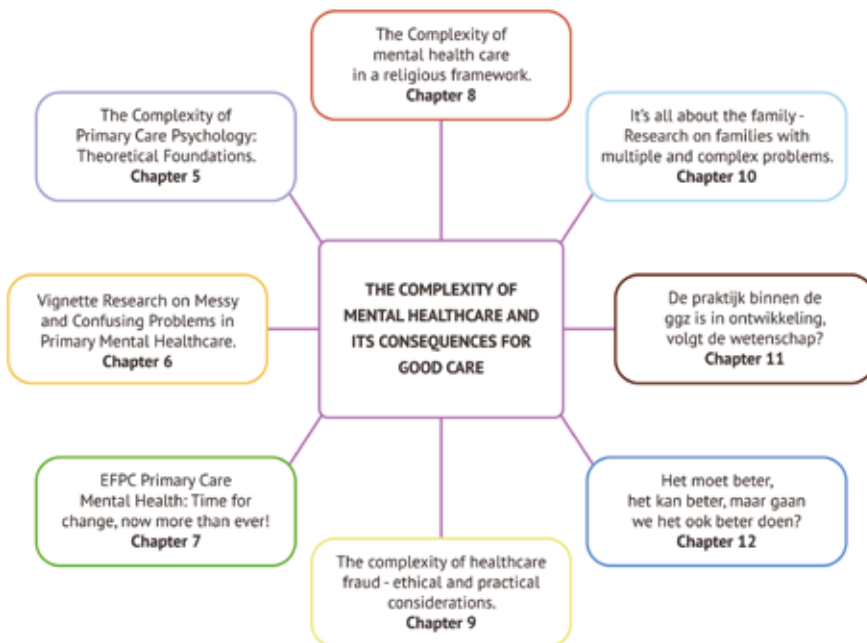
General Discussion



## Introduction

Conducting research in and on mental healthcare from the perspective of a novel scientific paradigm generates at least as many questions as it provides new insights. In a sector that – slightly provocative – is used to think in terms of problems and solutions, with measurable results based on pre-set indicators, research into the dynamics of the sector may be ‘interesting’. But it is unclear how these research results can benefit mental health services, or how society’s organized response to the phenomenon of mental suffering should look like. If one is not familiar with the paradigm and associated concepts and perspectives, then how can meaning be given to research results? And how does one determine the value of research results when the research methods are very different from traditional methodological approaches? I don’t have *the* answer, I just want to speak out and start a discussion on the subject. Getting to know the meaning and experiencing its value takes time...

To provide meaning to the different research findings from the different sub-studies, with different research methods, conducted in different parts of the mental healthcare system, eight propositions are presented. These propositions are linked to the previous chapters or publications. In addition, suggestions for further research are described.





## *Propositions*

### **1. Mental Healthcare is complex because of its interconnectedness with, and interdependencies on, other systems. Consequently, good care should also be considered from an ethically pluralistic perspective**

We need to focus less on 'what is' and look more at 'the dynamics' with a focus on its inter-connectedness and inter-dependencies (**chapter 5**). There is, after all, an inter-connectedness between treating people with mental problems, dealing with the family and/or employers, working together with other healthcare professionals, treatment within the rules of the mental healthcare act, struggling with dilemmas and having mixed feelings (**chapter 6**). We have to look critically at which sources of information are used (**chapter 5**) and how information can be shared and interpreted (**chapter 8**). From an ethical perspective, there is no objective formulation of good care or objective definition of healthcare professionals (**chapter 5**). Ethical values are always personal and should not be standardized, our perspective is limited to our subjective experience of it. Attention must be paid to the relationship between the knowing subjects and the object of knowledge (**chapter 5**). We need to avoid ethical monism and as much as possible and embrace ethical pluralism (**chapter 8**).

Interconnectedness and interdependency form a challenge for the medical mental health sector and for that part of the social care domain that focuses on the self-direction and recovery of people with mental issues. This issue is illustrated by the discussion about the concept of recovery. Recovery academies, self-direction and recovery centres and mental healthcare services all focus on the recovery of people with, in any case, mental problems. Medical mental healthcare is defined as 'care that the relevant professionals consider being part of the accepted arsenal of medical examination and treatment options and which is aimed at recovering or preventing aggravation of a mental disorder' (**chapter 8**). To be eligible for treatment under the Health Insurance Act, which in the Netherlands is equivalent to care by the medical mental health service, it is necessary to be diagnosed with a mental disorder. This means that mental healthcare is focused on the disorder and that the results of the care must at least show a reduction in the symptoms (**chapters 5 and 8**). But what if the disorder is interconnected and interdependent with life circumstances such as poverty, social exclusion or sexual abuse (**chapter 13**)? Is reducing the symptoms of a mental disorder that is presumed to be related to the maintenance of poverty and social exclusion, part of 'the accepted arsenal of medical examination and treatment options'? The development of a sustainable social network and support in finding suitable employment are not included.

This belongs more to the scope of interventions in the domain of social care. The collaboration between mental healthcare and the domain of social care is still limited at this moment and there is a lack of clarity as to what recovery actually means and who determines this. This is why equal co-creation (**chapter 11**) is so important because at present we are insufficiently able to solve the chicken-or-egg paradox. Co-creation based on equality and shared values offers both a good basis for further development and a considerable challenge for mental healthcare in a (currently) fragmented and competitive environment. (**chapter 8**).

Here lies a nice challenge for follow-up research: reframe the debate on good care and clarify the concept of recovery. Currently, the number of ego documents in which (former) clients express their dissatisfaction with current mental health care is increasing, and the perspective of experts by experience is highly valued. However, they are still not involved enough in the assessment of good care. In addition, the recovery movement is gaining momentum in a context where good care is defined by science. But we should not lose ourselves in a polarising debate about who is right and who is wrong. Rather, look at what definition of good care does justice to its intertwining with and dependence on other systems and contributes to an integrated approach to mental health support. I see an opportunity for knowledge centres such as Phrenos and Pharos, to play an important role in this.

**2. Complexity sciences provide a wealth of concepts and insights that can be of considerable use to the mental health sector. Science in mental healthcare should be intrinsically motivated to develop further, including in the direction of complexity sciences.**

According to the Dutch Research Council (NWO), science has to amaze, inspire and be at the heart of society. “Society relies on and participates in groundbreaking research because it makes an essential contribution to our future” (1). Thinking in terms of complex systems, strengthening the adaptive capacity, stimulating the learning abilities of an organization and obtaining insight into attractors and the factors that maintain an undesirable situation and can contribute to a healthier dynamic, are all in accordance with this approach (**chapter 11**). Analysing and developing feedback loops, taking emergence seriously as an added value within each system, can lead to new insights and possibly contribute to the structural problems within mental health services. Using the Cynafin Framework (**chapters 6, 8 and 9**) offers handles when reductionism and determinism are useful—in simple and complicated situations – and when complexity sciences can be of added value—in complex and chaotic situations.

One way to conduct follow-up research is to follow action research that is targeting the dynamics of the elements in mental health care as a complex system, using the concepts of the complexity sciences. One action research project that is doing just that is the so-called Ecosystem Mental Health. The Ecosystem Mental Health movement is or should be about equal collaboration and creating a broad, choice-based and joint supply of care elements around the citizen. It is about searching for effective co-creation with an emphasis on strengthening resilience rather than symptomatic cure of disorders. Within this development, the application of the concepts and methods of complexity sciences should be further elaborated.

**3. A complex system needs to be adaptive to address its challenges. Self-organisation, co-creation, feedback loops, emergence and attractors are concepts that can help to think through the system's adaptive capacity.**

A complex system, such as mental healthcare, is unpredictably influenced by other systems, both internal subsystems (e.g. team financial administration or management) and external systems (e.g. laws and regulations) and by local influences (**chapters 11 and 12**). The same principle applies at the level of individual treatment. The effects of a treatment aimed at clinical recovery (symptom reduction) can be influenced by problems in other areas of life (**chapter 6**). A system, therefore, needs space and competencies at micro, meso and macro level to address these influences (**chapter 11**). On the one hand, this seems obvious; after all, nobody can ignore internal and/or external influences. However, investigating for example where feedback loops play a role, is rare (**chapter 8**). Little research has also been done into the adaptive capacity of a mental health organization and its employees.

There are more than enough challenges for the mental healthcare sector. There are many financial challenges, there is a shortage on the labour market and judgement of success of mental healthcare is tilting to the negative. Organizations in the domain of social care are fragmented. In this complex situation, several mental health institutions and self-direction centres have to make use of probe-sense-respond approach and conducts experiments that are safe to fail. This requires extensive capacity for change and a learning organization structure. Follow-up research into the learning capacity of mental health institutions and organizations within the domain of social care can provide direction for this process. It should provide insight into the learning capacity of the organization as a precondition for further development.

**4. Emergence can mean hope for hitherto unsolved problems. A complex system contains multiple components that are interconnected and interdependent and interact with each other in unpredictable ways. This makes results on the one hand uncertain, but on the other may create emergence, which offers hope for solutions that are not yet known. Emergence cannot be forced into existence, but may be facilitated by multiple 'nudges' in the system, that jointly provide a degree of 'push' in the right direction.**

Emergence occurs when elements are combined and new properties and structures are created (**chapter 11**). In other words, emergence is the result of the interaction of all the elements in the system. This challenges the causality idea whereby there is a correlation between cause and effect. The cause is not to be found between one or more elements but in the dynamics of the system.

Project plans, Administrative Agreements and policy documents rarely mention emotions and norms and values of both client and care professional. Nor do they mention specific culture of a mental health service (**chapter 8**). And yet, treatment in mental healthcare is fraught with emotions, norms and values (**chapter 6**). The idea that all those involved are unbiased, seems to be an illusion (**chapter 6**). This is not surprising, the complexity of daily practice is difficult to capture in a model (**chapter 10**) or in a limited number of words (**chapter 6**).

At the start of a project or research plan, it is usual to describe a clear expected outcome (determinism). This encourages, certainly when funding is dependent on it, resistance to unpredictable developments. Emergence happens, predicted or not, but is in danger of being lost as valuable information.

If we assume that in project plans and policy papers, there is virtually no room for emotions, for example, while emotions are inseparably human, then it is plausible that emotions will emerge as an emergent property within a co-creation. We don't want to exclude emotions in mental healthcare and should, despite the uncertainty, embrace emergence. Emergence is in the end, just a part of a project or policy *with hopeful expectations*.

Action research represents a much way to study emergence, as it allows for flexible adjustments along the way and is not deterministically oriented. Rather, it accepts that outcomes can be 'nudged' into emergence as a result of complex, non-linear and non-predictable changes taking place during the flexible and adaptable progress of the process.

**5. Uncertainty requires trust and co-creation based on collective values. Trust in the mental healthcare sector and in authorities is under pressure. The joint (re)formulation of shared values in cocreation can contribute to the restoration of mutual trust and confidence and a redefinition of what constitutes good care.**

When it comes to good care, evidence-based practice is held in high esteem. But proven care is not necessarily good care (**chapter 2**) and, paradoxically, the great majority of interventions in mental health care and medicine in general, are lacking in high quality evidence (2). Furthermore, people experience different challenges to their mental health from region to region and even from neighborhood to neighborhood (**chapter 12**). Good care facilitates recovery, and recovery is more than just clinical recovery, just as recovery is more than the measurable result (**chapters 4 and 9**). Building a new perspective on mental health, together with all stakeholders is a good way of ensuring that each individual can be supported to help them meet their complex needs (**chapter 7**). However, how do you do this in a context where distrust in healthcare and the authorities is robust and growing (3, 4) despite the fact that regaining mutual trust in healthcare has been a top priority for years (5)?

Co-creation calls for equal collaboration and meaningful use of a wide range of information sources, referred to as collective making (6). To achieve this, it is important to recognize the inequality of power and influence. When we talk about mental healthcare in the regular debate, we are mainly talking about the care that falls under the Health Insurance Act with large regional care institutions for mental health. The employers' association of these mental healthcare institutions, GGZ Nederland, is the representative in this respect. Client organisations and local self-management centres and recovery academies are represented by MIND, but at the level of local co-creation, they have a different position than the local mental healthcare institution. The dozens of local informal support organizations and foundations that 'do what is necessary' at the local level are hardly visible. If we want to move towards equal co-creation with shared values, we will have to think about how we want to shape this desired equality in the future. Are we going to organize the promotion of mental health in large organizations that take care of all dimensions of recovery? Does this offer overview and (the appearance of) manageability, including risks of bureaucratic processes and quality systems? Or can we bear the uncertainty and trust local organizations and foundations that are part of the neighborhood, working with a mix of experience experts, volunteers and professionals?

This issue deserves to be considered and discussed with an open mind, based on our common goal: recovery of the client. This can be done with the use of co-creation sessions or Socratic Dialogue. By addressing this issue, a good foundation can be laid for the intended equal co-creation based on shared values.

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**6. Self-organisation gives back the autonomy of mental healthcare professionals. It is not the caregiver who needs to control the system through protocols, it is the mental healthcare system that needs to ensure that the desired feedback loops are rewarding.**

Self-organisation is necessary as response to various internal and external disturbances and conflicts (**chapters 5 and 6**). The adaptive capacity of the system and the possibilities that actors have to optimise the system through self-organisation and cocreation, allow the system to adapt to unexpected situations (**chapter 11**).

Self-organisation is important, especially for individual healthcare professionals, for several reasons. Firstly, to be able to work on recovery at the individual level, when recovery is not the same as the way in which support for recovery is organised. If necessary, the individual care professional should collaborate with a self-direction centre and/or a recovery academy, not hindered by the way care is financed (**chapters 6, 8 and 10**). Secondly, through the space provided for self-organisation, healthcare professionals can learn to see and deal with emergence. This emergence should then not remain hidden out of fear of act in an unscientific manner (**chapter 6**) but be discussed as an action in the context of their social responsibility (**chapter 9**). Thirdly, all this feeds a healthy debate on what good care is or should be.

To properly comprehend and address the robust problems within the mental healthcare system, one needs to develop knowledge of the dynamics of the complex system (**chapters 5 and 11**). This is, according to Morin's holographic principle, formulated as follows: you cannot understand the parts if you have not enough knowledge of the whole and vice versa (**chapter 3**). This is what is meant by an ecosystem mental health; it is a network of different systems that are interconnected and interdependent (**chapter 11**). Constraining healthcare professionals to adapt their care to the complexity of the case also deprives the system of the opportunity to improve as a whole. Analysing feedback loops, which include interconnectedness and interdependency, may give a better idea of where the system can be improved. As an example, the cost development within the mental healthcare system, despite (or perhaps as a result of) all of the interventions, clearly shows a positive feedback loop: where factors influence each other cumulatively. It is interesting to analyse this feedback loop instead of announcing new measures within the same framework.

**7. Mental health is connected to its context. Mental health is interconnected with and interdependent on quality of life, meaningfulness, participation, daily functioning and/or bodily functions. How mental health is approached and assessed should be in line within these levels of interconnectedness and interdependency.**

The client's story is almost never limited to the symptoms of a mental disorder (**chapters 10 and 13**). It often includes everyday life experiences with friends and family, work, related to their socio-economic status and social participation, negative experiences in the past and coping mechanisms (**chapters 6 and 10**).

People are not intrinsically separate from their context: their social networks, their norms and values and their economic and cultural capital also influence their health, what it means to them and the way they deal with it. This context can also determine the treatment plan. The emphasis on scientific, empirical knowledge in medical education conflicts with this insight. It yields a schizophrenic situation: it is a human science that we are approaching without using the humanities (5).

The mental health of citizens can thus be promoted not only by psychiatrists and psychologists within the Health Insurance Act. Access to support for improving mental health should be low-threshold and co-created (**chapters 7 and 11**). This is to prevent fragmentation and accumulation of care and to enhance self-direction (**chapter 10**). The needs of the population should be in line with the care and/or support that is given (**chapter 12**). The presumption that in urban areas and areas with a higher density of mental health professionals, mental healthcare is more expensive and disconnected from the needs profile of the population (**chapter 12**), and the fact that the costs of the specialised mental health services have grown while the number of clients has decreased (7), calls for reflection on a different allocation of financial resources.

The phenomenon of interconnectedness and interdependency between mental health and its context calls for a more dynamic approach (**chapter 8**). Explicit attention should be given to issues of diversity where epistemic injustice and different cultural norms and values are integrated. That is easier said than done, but never the less feasible. A reformed mental healthcare system, where a peer-to-peer collaboration is the default attractor, can reduce the need for hierarchical structures of authorities. Focussing on recovery is focussing on all dimensions of positive health as well as dealing with the interconnectedness and interdependency of these dimensions.

**8. The days of working as a function of the status quo are over, action is needed. All stakeholders have a social responsibility to engage in dialogue when good care is at risk.**

When we understand the complexity of mental health and accept the consequences for the judgement of good care, work and following procedures are not acceptable anymore (chapter 9). Established rights must be able to be challenged for the sake of necessary change (chapter 12). The right thing to do, Hannah Arendt promotes, is to act: to speak

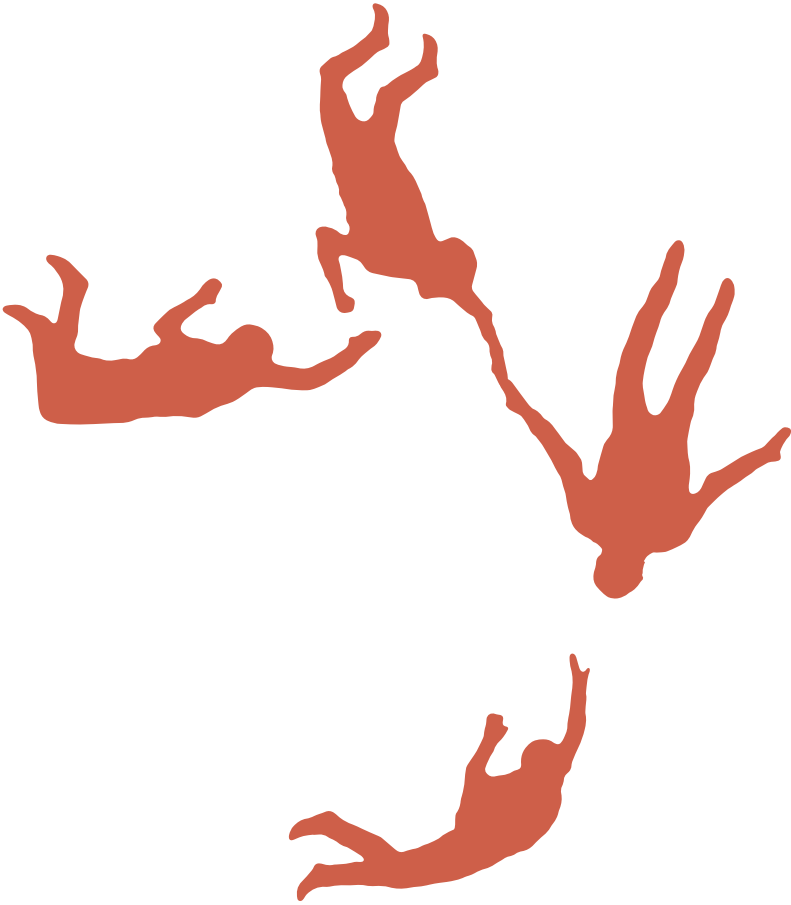
out and start a discussion on the topic (chapter 11). This is exactly what this PhD thesis is about: to share knowledge, to speak out and start a discussion.

There is no single solution to complex problems, but rather a direction for solving them. There are no professionals or organizations that do it rightly or wrongly, but there is an obligation for equal co-creation. Scientific knowledge related to mental health is important, as is our ability to integrate and connect multiple sources of knowledge. There is no battle between classic scientific methods and complexity sciences, but rather an insight into when which paradigm contributes to the improvement of mental health. Science can provide insight and contribute to improving mental health, even without determining the future.



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# Chapter 15

Suggestions for follow-up research



## *Suggestions for follow-up research*

If mental health is interconnected to, for example, social participation, experiencing a meaningful life and a certain degree of livelihood security, then it seems obvious that recovery of mental problems must also be linked to social participation, experiencing a meaningful life and a certain degree of livelihood security. This requires, as Edgar Morin puts it: *“We need a kind of thinking that reconnects that which is disjointed and compartmentalised, that respects diversity as it recognises unity, and that tries to discern interdependencies. We need a radical thinking (which gets to the root of problems), a multidimensional thinking, and an organisational or systemic thinking”*.

The Ecosystem Mental Health movement sets the stage for transformation by taking this interconnectedness and interdependency seriously, working as a coherent network project across different domains. A network that brings together all the competencies and action perspectives needed to facilitate change and participation and create new perspectives. This endeavour is persistent across different contexts of mental suffering, in a lively and learning system of collaboration. GEM is based on a strong shared vision of values-based work. A web of connections around the patient on the one hand, but also a jumble of complexity on the other. This requires extensive research into the potential success factors and pitfalls. Not to prove in advance the effectiveness of this Ecosystem Mental Health, which invariably is not possible with complex systems, but to do research on the expected dynamics of GEM. This involves looking at possible feedback loops and what could become the default attractor.

An attractor is a state in which a dynamic system evolves. Looking at the current attractor, we see, for example, that treating patients, where measurable positive results on symptom reduction can be expected, are ‘attractive’. As a result, patients with multiple and complex problems were somewhat left out – as these unlikely to show linear improvement in the domain of measurable symptom reduction. We also noticed that within the current attractor, mental health institutions in urban areas and areas with higher mental health care density show more intensive mental health activity which is dissociated from the population profile. This suggests that it is ‘attractive’ to provide supply-driven care.

What could be the attractor when an Ecosystem Mental Health is developed within the context of the current scientific paradigm, with funding divided under different laws and regulations and the recent implementation of the Integrated Care Agreement? In an Ecosystem Mental Health where people can find low-threshold support to strengthen their resilience and mental health, there are many options. Will it become ‘attractive’ to

'shop around' extensively which will increase rather than decrease healthcare costs? Or will the patient not see the wood for the trees because *everyone* offers recovery support in co-creation? What kind of attractor can evolve if co-creation leads to colossal care organisations (shared overhead, easier in tenders etc.) offering everything from peer-to-peer support and day-care to recovery colleges and specialised mental health treatment? Which feedback loop most supports patient self-direction?

By translating policy (e.g. the integrated care agreement in combination with GEM) into feedback loops and from there into attractors, insight can be gained into possible scenarios. In this, the current scientific paradigm and funding are also included. Scenarios within this context consist of descriptions of the complex system containing the feedback loops and the possible attractor. Proposals can then be developed to adjust the trajectory, if necessary, to where the attractor seems to evolve.

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# **PART IV**

## **Chapter 16**

Summery



*What is the complexity of mental healthcare and what significance does this complexity has for determining good care?*

In recent decades we have tried to grasp the complexity of mental healthcare in terms of ‘to measure is to know’ (1) (**chapter 1**). The questions of what a mental health problem is, what can we know about mental health problems and what should we do to remedy mental health problems were answered almost exclusively by science, based on the Newtonian paradigm with its reductionism and determinism (**chapter 5**). The question of “what may I hope”, disappeared into the background, as did a meaningful debate about good care (2, 3). The classical understanding of science was supposed to make mental healthcare efficient, but is this true (**chapter 12**)?

Regrettably, primary care psychologists, emerging from self-organisation in co-creation with the general practitioner and focusing on the context of psychological complaints, did not fit well in this Newtonian paradigm and found themselves – after a system transformation – in a tight spot (4–6). Also partly as a result of the introduction of market principles in mental healthcare, the collaboration between the actors involved was turned into a competition for scarce financial resources (7).

Mental healthcare and mental problems are rarely a stand-alone issue (**chapters 6 and 10**) and to change this, interventions are needed at various levels (**chapter 7**). Finding one’s way through the forest of rules and linear knowledge can be frustrating (**chapters 9 and 13**)(8). Mental healthcare shows characteristics of “a wicked problem” that could not be satisfactorily answered with a lot of uniform scientific research, administrative agreements, care transitions and transformations (**chapters 1 and 4**).

Providing mental healthcare is complex and requires more than scientific knowledge of effectively proven treatment methods for well-defined mental disorders alone (**chapter 8**). Recovery cannot be limited to clinical recovery (symptom reduction, insight into behavioural problems and coping with one’s limitations), it is so much more. It includes existential recovery (hope, empowerment, spiritual well-being), functional recovery (taking on responsibilities, having a job and/or education, having a place to stay), physical recovery (general health, a healthy lifestyle and balance between activity and rest) and last but not least social recovery with meaningful relationships, feeling connected to one’s local community and acceptance of one’s social status (**chapters 8 and 13**). Good care cannot be determined by just following the rules, there are too many rules and regulations. These rules are mostly linear and address a single aspect of the mental healthcare system. Mental healthcare is also about access, cocreation, education, inequality, information technology, model of care, prevention, self-care, spirituality and

workforce development (**chapter 7**) (9). Good care is interconnected with the lives and personal needs of recovery (**chapter 13**) To change the current way of thinking, we need a new vocabulary to reconnect what is disjointed and compartmentalised, that respects diversity and learns us more about the interconnectedness and interdependencies. It is time for action (**chapter 9**).

Using complexity sciences in mental healthcare research is needed. Thinking in terms of complex systems, strengthening the adaptive capacity, stimulating the learning abilities of an organization and obtaining insight into attractors and the factors that maintain an undesirable situation and contribute to a healthier dynamic, are all in accordance with this approach (**chapter 11**). Analysing and developing feedback loops, taking emergence seriously as an added value within each system, can lead to new insights and possibly contribute to the structural problems within mental health services. Using the Cynafin Framework (**chapters 6, 8 and 9**) offers handles when reductionism and determinism are useful—in simple and complicated situations—and when complexity sciences can be of added value—in complex and chaotic situations.

The mental healthcare sector is in motion. What constitutes mental health is being formulated in broad terms, making the interconnectedness and interdependencies debatable (10). What we are able to know is being carefully considered, not only by those with lived experience (experts by experience) (11) and the self-direction and the recovery centres (12, 13), but also by science (14). What we are supposed to do is currently being thought up, discussed and developed by an interdisciplinary community (15–17) (**chapter 11**). What can we hope for is still in its infancy, but there is plenty to hope for. We hope for equal collaboration between all actors in the mental health ecosystem where the person with mental health issues can choose how to work on his/her recovery (**chapter 15**). We hope that by doing the right thing collectively—based on shared values—self-organisation will be strengthened and mental healthcare will become an added value rather than a financial cost. We hope that uncertainty will be given a positive connotation, as an invitation to widen or deepen our competencies. We hope that the bottom up activities of the self-direction and recovery movement, encouraged by the Nederlandse Vereniging voor Zelfregie en Herstel [Dutch Association for Self-direction and Recovery], continue to nourish this movement (18, 19). We hope that the complexity of mental healthcare will be acknowledged and embraced, creating room for a different distribution of financial resources and new ways of developing knowledge. Let us start today, filled with hope, by creating public space for (Hannah Arendt's) action and deliberation.

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# Chapter 17

Samenvatting





*Wat is de complexiteit van de geestelijke gezondheidszorg en welke betekenis heeft deze complexiteit voor het bepalen van goede zorg?*

In de afgelopen decennia hebben we geprobeerd de complexiteit van de geestelijke gezondheidszorg te vatten in termen van 'meten is weten' (1) (**hoofdstuk 1**). De vragen wat een psychisch probleem is, wat we kunnen weten over psychische problemen en wat we moeten doen om psychische problemen te verhelpen, werden vrijwel uitsluitend beantwoord door de wetenschap, gebaseerd op het Newtoniaanse paradigma met zijn reductionisme en determinisme (**hoofdstuk 5**). Wat mag ik hopen, verdween naar de achtergrond, evenals een zinvol debat over goede zorg (2, 3). Het klassieke wetenschapsbegrip werd verondersteld de geestelijke gezondheidszorg efficiënt te maken, maar is dat wel zo (**hoofdstuk 12**)?

Helaas pasten de eerstelijnspsychologen, voortgekomen uit zelforganisatie in co-creatie met de huisarts en gericht op de context van psychische klachten, niet goed in dit Newtoniaanse paradigma en kwamen zij – na een systeemtransformatie – in het nauw (4–6). Mede als gevolg van de introductie van marktprincipes in de geestelijke gezondheidszorg is de samenwerking tussen betrokken actoren verworden tot een concurrentiestrijd om schaarse financiële middelen (7).

Geestelijke gezondheidszorg en psychische problemen staan zelden op zichzelf (**hoofdstuk 6 en 10**) en om dit te veranderen zijn interventies op verschillende niveaus nodig (**hoofdstuk 7**). Je weg vinden in een woud van regels en lineaire kennis kan frustrerend zijn (**hoofdstuk 9 en 13**, (8)). De geestelijke gezondheidszorg vertoont kenmerken van een wicked problem dat niet bevredigend beantwoord kon worden met veel uniform wetenschappelijk onderzoek, bestuurlijke afspraken, zorgtransities en transformaties (**hoofdstuk 1 en 4**).

Het bieden van geestelijke gezondheidszorg is complex en vereist meer dan wetenschappelijke kennis van effectief bewezen behandelmethoden voor welomschreven psychische stoornissen (**hoofdstuk 8**). Herstel kan niet beperkt worden tot klinisch herstel (symptoomreductie, inzicht in gedragsproblemen en het omgaan met de eigen beperkingen), het is zoveel meer. Het omvat existentieel herstel (hoop, empowerment, spiritueel welzijn), functioneel herstel (verantwoordelijkheden op je nemen, een baan en/of opleiding hebben, een plek om te verblijven), lichamelijk herstel (algemene gezondheid, een gezonde levensstijl en balans tussen activiteit en rust) en last but not least sociaal herstel met betekenisvolle relaties, je verbonden voelen met je lokale gemeenschap en acceptatie van je sociale status (**hoofdstuk 8 en 13**). Goede zorg kan niet worden bepaald

door alleen maar de regels te volgen, daarvoor zijn er te veel regels en voorschriften. Deze regels zijn meestal lineair en hebben betrekking op een enkel aspect van de geestelijke gezondheidszorg. Geestelijke gezondheidszorg gaat ook over toegang, cocreatie, onderwijs, ongelijkheid, informatietechnologie, zorgmodel, preventie, zelfzorg, spiritualiteit en ontwikkeling van arbeidskrachten (9) (**hoofdstuk 7**). Goede zorg is verbonden met het leven en de persoonlijke behoeften van herstel (**hoofdstuk 13**) Om de huidige manier van denken te veranderen, hebben we een nieuw vocabulaire nodig om wat onsamenhangend en verkokerd is weer met elkaar te verbinden, dat diversiteit respecteert en ons meer leert over de onderlinge verbondenheid en de onderlinge afhankelijkheden. Het is tijd voor actie (**hoofdstuk 9**).

Het gebruik van complexiteitswetenschappen in onderzoek naar geestelijke gezondheidszorg is nodig. Het denken in termen van complexe systemen, het versterken van het adaptief vermogen, het stimuleren van het lerend vermogen van een organisatie en het verkrijgen van inzicht in attractoren en de factoren die een ongewenste situatie in stand houden en bijdragen aan een gezondere dynamiek, sluiten aan bij deze benadering (**hoofdstuk 11**). Het analyseren en ontwikkelen van feedback loops, waarbij emergentie serieus wordt genomen als een toegevoegde waarde binnen elk systeem, kan leiden tot nieuwe inzichten en mogelijk bijdragen aan de structurele problemen binnen de geestelijke gezondheidszorg. Het gebruik van het Cynafin Framework (**hoofdstuk 6, 8 en 9**) biedt handvatten wanneer reductionisme en determinisme zinvol zijn – in eenvoudige en gecompliceerde situaties – en wanneer complexiteitswetenschappen van toegevoegde waarde kunnen zijn – in complexe en chaotische situaties.

De sector is in beweging. Wat geestelijke gezondheid is, wordt in brede termen geformuleerd en de onderlinge samenhang en afhankelijkheden worden bediscussieerd (9). Wat we kunnen weten wordt zorgvuldig afgewogen, niet alleen door ervaringsdeskundigen (9) en zelfregie- en herstelcentra (12, 13) maar ook door de wetenschap (14). Wat ons te doen staat, wordt momenteel door een interdisciplinaire gemeenschap bedacht, besproken en ontwikkeld (15–17) (**hoofdstuk 11**). Waar we op kunnen hopen staat nog in de kinderschoenen, maar er is genoeg om op te hopen! We hopen op een gelijkwaardige samenwerking tussen alle actoren in het ecosysteem van de geestelijke gezondheidszorg waarbij de persoon met psychische problemen zelf kan kiezen hoe hij/zij aan zijn/haar herstel wil werken (**hoofdstuk 15**). We hopen dat door collectief het juiste te doen – gebaseerd op gedeelde waarden – zelforganisatie wordt versterkt en dat geestelijke gezondheidszorg een waarde wordt in plaats van een kostenpost. Wij hopen dat onzekerheid een positieve connotatie zal krijgen, als een uitnodiging om onze competenties te verbreden of te verdiepen. Wij hopen dat de bottom up activiteiten van de zelfregie- en herstelbeweging, aangemoedigd door de Nederlandse Vereniging voor Zelfregie en Herstel, deze beweging blijven voeden (18, 19). Wij hopen dat de complexi-

teit van de geestelijke gezondheidszorg wordt erkend en omarmd, waardoor er ruimte ontstaat voor een andere verdeling van financiële middelen en nieuwe manieren van kennisontwikkeling. Laten we vandaag vol hoop beginnen met het creëren van publieke ruimte voor (Hannah Arendt's) actie en deliberatie!

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- 4 Smit D, Derksen JPd. Einde van dertig jaar eerstelijnspsychologie? Psychopraktijk. 2014;6(2):25-7.
- 5 Smit D, Bosch FD. Het einde van de solist? Psychopraktijk. 2013;5(6):32-4.
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- 7 Smit E. Bezuiniging: samen werken, niet samen vechten! GZ-psychologie. 2011;3(5):12-5.
- 8 Smit D. Worstelende professionals en onwetende cliënten. Sociaal Bestek : Tijdschrift voor werk, inkomen en zorg. 2018;80(4):59-61.
- 9 De Lepeleire Jan SD, Hill Lisa, Walton Ian, Kendall Sally. EFPC Mental Health Position Paper. Internet; 2020 December.
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- 12 Verheul M. GEM Deventer - Ecosysteem Mentale Gezondheid. Out of the Box TV; 2022.
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# Dankwoord





## Dankwoord

Het doen van tien jaar wetenschappelijk onderzoek en drie jaar schrijven en schaven aan een proefschrift vraagt om een optimale context van stimulans en support (naast voldoende financiële middelen). Hoe complex mijn onderzoeksthema en context ook was, zo ongecompliceerd waren de mensen om mij heen!

Het enthousiasme van Paul van der Gun “complexiteitswetenschappen is écht iets voor jou Dineke!” was het prille begin van dit onderzoek. Harry Kunneman, Kees Pieters en Anne Helms van de Universiteit voor Humanistiek ben ik dankbaar voor de stimulerende en prikkelende gesprekken bij aanvang van mijn promotieonderzoek.

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Sharing amounts of passion for mental healthcare, and facing hefty challenges with humor, describes my friendship with and the support I received from Ian Walton, Jan de Lepeleire and Lisa Hill, of the European Forum for Primary Care. For more than 10 years, we have been exchanging knowledge and experience, conducting scientific research as well as sharing joys and sorrows. Their international perspective constantly pulled me out of my Dutch bubble, widening my perspective. Ian, thank you so much for correcting my Denglish again and again.

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1. Smit D. Over meten is weten en de behoefte aan zekerheid.... *Psychopraktijk*. 2010;2(3):23-6.
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5. Prins M, Verhaak P, Smit D, Verheij R. De positie van de eerstelijnspsycholoog in de eerstelijns-ggz. *Huisarts en wetenschap*. 2012;55(4):146-50.
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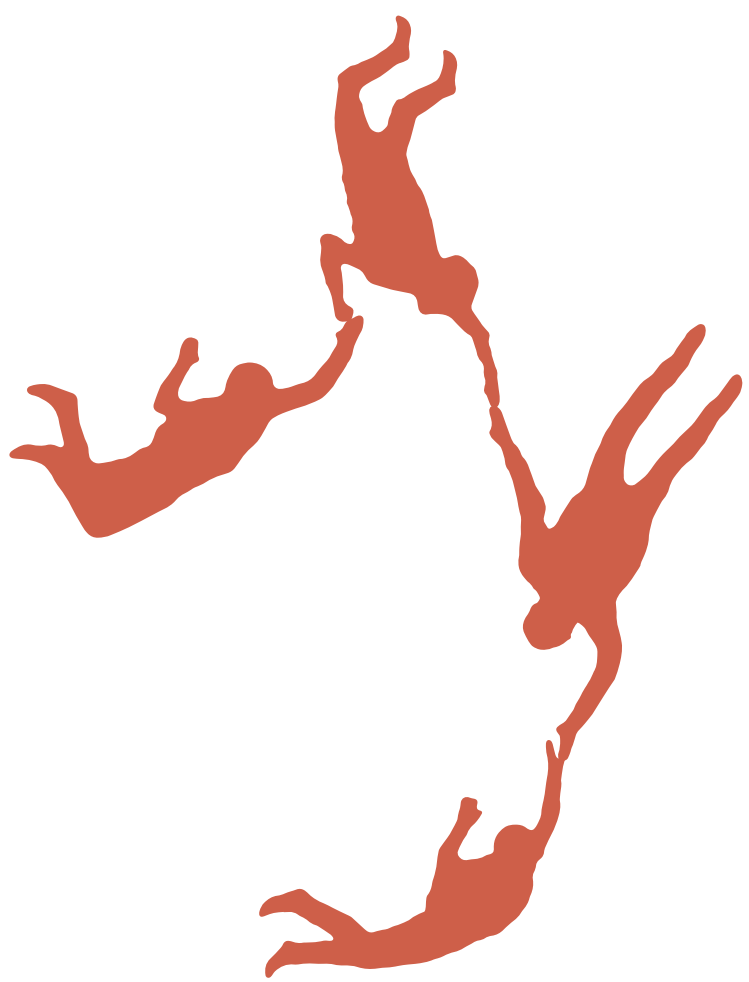


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24. Smit D, Derksen J. The complexity of healthcare fraud – ethical and practical considerations. *ethic@ – An international Journal for Moral Philosophy*. 2020;19(2):367-85.
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26. Smit EH. It's all about the Family: Research on Dutch Families with Multiple and Complex Problems. *Canadian Journal of Family and Youth / Le Journal Canadien de Famille et de la Jeunesse*. 2022;14(3):106-30.
27. Smit, D., & van Os, J. (2022a). De praktijk binnen de ggz is in ontwikkeling, volgt de wetenschap? *Tijdschrift voor psychiatrie*, 692-695.
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**List of conference  
presentations**



- 2022 European Forum for Primary Care conference**, 2022 Genth Belgium. *Integrated Community Care: a new opportunity for Primary Care*. Presentation EFPC working group mental health: *The challenge of Mental Health*. Presentation with dr. R. Keet, chair of EUCOMS: *From human rights to the expertise of the patient. The long and winding road to community mental health*.
- Closing conference European Primary care Multi-professional Researcher network (PRIMORE)** at Western University Bergen, Norway. Presentation: The complexity of primary care and interprofessional cocreation. Presentation: Developments in Mental Healthcare in the Netherlands.
- 2021 European Forum for Primary Care conference**, 2021 Bergen (online). *What is the current and future role of Primary Care in managing Long-Covid?* Presentation EFPC working group mental health.
- 2020 European Primary care Multi-professional Researcher network (PRIMORE) webinar**, Interprofessional Research in Primary Care. Presentation on the complexity of interprofessional research, working together with a diverse perspective.
- PRIMORE Masterclass: Interprofessional PC Research**. Online, 27, 28 & 29 September 2020 and supervised a group of healthcare professionals for six months from different countries and educational backgrounds towards a collaborative research proposal.
- 2019 European Primary care Multi-professional Researcher network (PRIMORE) launch meeting**, Utrecht 29th March 2019. Presentation: Increase of interest and respect for each other's profession among mental health primary and secondary care professionals.  
Webinar European Forum for Primary Care. Presentation of the topics of the EFPC Position Paper Mental Health in Primary Care 2019, prioritizing the topics.
- 2018 European Forum for Primary Care conference Heraklion**, Crete 23–25 September 2018. *Vulnerability and Compassion: The role of Primary in Europe. How to overcome the austerity period*. Presentation: Mental health in primary care: austerity or chance?
- European General Practice Research Network conference**, Lille University School of Medicine, 10–13 May 2018. *Changing doctors for a changing world: How to face the future of primary care?* Presentation: Developing Mental Health in Primary Care: Investigating a European Proposal.
- 2017 European Forum for Primary Care conference**, Porto 24–26 September 2017. *The Citizen Voice in Primary Care; a social commitment to 'health for all!'* Presentation EFPC working group: All citizens, different perspectives: from experience experts in mental health to healthcare professionals and scientists.

- European Forum for Primary Care conference**, Porto 24–26 September 2017. *The Citizen Voice in Primary Care; a social commitment to 'health for all'!* Presentation with Limke Schopman peerworker: *Who am I? A citizen? A (n ex) client? A peer to peer professional in mental health?*
- 2016 European Forum for Primary Care Riga conference**, 4–6 September 2016. *Crosscutting Informal Care and Professional Primary Care*. Presentation EFPC working group: Mental health in primary care: when (not) to use disease-orientated guidelines
- 2015 World Federation for Mental Health (WFMH) & French Psychiatrist Partners**. International Mental Health Congress, 28–30 April 2015, Lille France. *Mental health for all. Connecting people and sharing experiences*. Presentation: Sharing peer to peer knowledge and experiences about mental healthcare. Presentation: A dynamical bio-psychosocial model: a generalist perspective on mental healthcare.
- European Forum for Primary Care Amsterdam conference**, 30 Aug–1 Sept 2015. *Integrated Primary Care: Research, Policy & Practice*. Presentation EFPC working group: From practice to research (and back to practice again).
- 2014 Society for Chaos Theory in Psychology & Life Sciences**, Nijmegen, Netherlands. *6th International Nonlinear Science Conference, 20–22 March 2014*. Presentation: Complexity of Primary Care Psychology.
- 2013 European Forum of Primary Care, Galatasaray University**, Istanbul, Turkey, September 9/10, 2013. *Balancing The Primary And Secondary Care Provision For More Integration and Better Health Outcomes*. Presentation EFPC working group: Primary and secondary mental care: equality and complementarity.
- 2012 Critical Complexity Thinking. The next steps**. 12 September 2012, University of Humanistic Studies, Netherlands. Presentation: *What is the complexity of primary care psychologists as normative professionals?*
- ECCS Satellite Meeting Critical complexity thinking**. *Exploring the entanglement of causal and ethical complexity in organizations and professions*. Thursday, September 6, 2012, Brussels. Presentation: *Critical Complexity in Primary Care Psychology*.
- The European Primary Care Forum**, 2012 conference. *The Future of Primary Healthcare in Europe*. Goteborg, Sweden. September 3/4, 2012. Presentation: Interconnected Ethics.
- International Conference Good Work. The Ethics of Craftsmanship**. 17 October 2012. University for Humanistic studies. Presentation: *The Complexity of Good Care*.
- 2011 21st Annual International Conference of the society for chaos theory in psychology & life sciences**. August 4–6, 2011. Chapman University, Orange California USA. Presentation: *Nonlinear-minded*

*professionals in a linear organized environment. Presentation: Understanding the complexity of primary care psychologists.*

**International Congress on Qualitative Inquiry.** *Qualitative Inquiry and the Politics of Advocacy.* May 18–21st 2011. The University of Illinois at Urbana–Champaign, USA. Presentation: *Normative judgments by primary care psychologists.*

**2010 4th International Nonlinear Science Conference.** March 15–17, 2010. University of Palermo, Palermo, Sicily, Italy. Presentation: *Do the numbers tell the tale?*





