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Towards an Information Strategy for the Manic-Depressive Disorder Chain-of-care

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Abstract: This article presents the results of the chain analysis of the Manic-Depressive Disorder chain-of-care according to the standard method of Chain-Computerisation (see the appendix to this article). A chain analysis aims at determining (beforehand) the chance of success of a chain information system. A theoretical and practical introduction to this chain analysis methodology can be found in the founding article in this journal.[1] This chain analysis is part of the Chain Landscape Research Programme at the Department of Information and Computing Sciences of the University of Utrecht. Conclusions are drawn with regard to a suitable information strategy for this chain and to potential impacts on relevant current or intended IT-projects.[2]

Samenvatting: In dit artikel worden de resultaten beschreven van de ketenanalyse van de Manisch-Depressieve Stoornis-zorgketen, uitgevoerd volgens de standaardmethode van Keteninformatisering (zie de bijlage van dit artikel). Op basis van een ketenanalyse kan (vooraf) de kans op succes van een keteninformatiesysteem worden bepaald. Een theoretische en praktische introductie op de methodologie van ketenanalyses is opgenomen in het founding article van dit tijdschrift. Deze ketenanalyse is onderdeel van het Ketenlandschapsonderzoek aan het Departement Informatica van de Universiteit van Utrecht. Conclusies worden getrokken met het oog op een passende informatiestrategie voor de Manisch-Depressieve Stoornis-zorgketen en de mogelijke impact op relevante huidige en geplande ICT-projecten.

Keywords: chain-computerisation, chain analysis, information strategy, manic-depressive disorder

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1 Grijpink, J.H.A.M. (2010). Chain analysis for large-scale communication systems: a methodology for information exchange in chains. *Journal of Chain-computerisation, 1*.

2 We thank D. van Schie, J. Wouters, M. Blom and F.J. van der Span for their contribution.

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1. General description of the MDD chain-of-care[3]

Manic-Depressive Disorder (MDD) is characterised by alternating episodes of mania – during which the patient is exuberant and decisive – and depression, during which the patient is withdrawn and inactive. These often extreme mood swings can have major consequences for the patient and those around him. MDD is incurable; the treatment is focused on learning to deal with the mood swings inherent in the disorder. The challenge of the MDD chain-of-care is, therefore, to improve the quality of life for patients with MDD. It is difficult to diagnose MDD and subsequently to gear the treatment to the mood swings of the patient. That is because the mood swings alternate, the difference with respect to normal mood changes is blurred and other psychiatric disorders may also play a role. Moreover, often the patient himself does not recognise the mood swings and is not always disciplined about attending therapy and taking his medication. Without proper signalling of these mood swings, there is the danger that intervention comes too late and is not well-balanced (too much or too little). Thus, the patient's mood can reach such an extreme that hospitalisation of the patient becomes essential or that the patient seriously harms himself or those around him.

In the MDD chain-of-care, a great many parties are active. Family doctors, psychologists and psychiatrists play a role in making a correct diagnosis and in the treatment of MDD; the Knowledge Center for Bipolar Disorders [Kenniscentrum Bipolaire Stoornissen (KenBis)] and the Trimbos Institute provide valuable information for patients, those around them and those treating them; the Society for Manic Depressives and Their Families [Vereniging voor Manisch Depressieven en Betrokkenen (VMDB)] plays an important role in the protection of interests, the contact with fellow sufferers and in the counselling and information provision of patients and their environment.

[3] The Manic-Depressive Disorder is also denoted as a 'bipolar disorder'.

MDD is a complicated clinical picture with various forms of expression that requires a great deal of expertise and experience in order to regulate and monitor the patient correctly. The suicide risk with bipolar disorder is considerable. That demands effective teamwork between the primary and secondary lines of healthcare. Generally, family doctors have too few patients with bipolar disorder to be able to recognise the disease and to be able to take part in the local consultation. They also do not have enough time available for MDD patients (10-20 minutes per consultation). Moreover, a patient does not often seek medical assistance during the manic phase. The diagnosis and medication of bipolar disorder belongs, therefore, in the hands of the psychiatrist. The basic medication is lithium or, in the case of so-called rapid cyclers, carbamazepine. Depending upon the episode, a neurolepticum or antidepressant is administered. That means that the medication is dependent upon the phase which the bipolar patient is in. As soon as an MDD patient is stabile, the treatment can be passed onto the family doctor.
Subsequently, the mutual communication between second-line healthcare professionals and independent psychiatrists is of major significance. National guidelines for diagnosis and treatment are generally well adhered to within facilities, but it is signalled that self-employed psychiatrists apply the guidelines less strictly.

After the initial diagnosis, the MDD chain-of-care also comes into action when the mood of a patient threatens to become extreme or when the therapist or therapists involved see that a mood swing is imminent. This is all about stabilising the patient as quickly as possible in order to curtail the damage. The treatment consists of a combination of medication, psycho-education, supportive counselling and, if necessary, specifically-focused psychotherapy. Advice and counselling of the partner and other close family and friends are essential here, also because they can play a significant role in the early signalling of mood swings.

For the treatment, supportive resources are available, such as the life chart, the emergency plan, the crisis card and e-learning programmes for doctors. There are also instructions and decision trees for therapists in order to help them steer the therapy and prescribe the correct medication. In the MDD chain-of-care, no large-scale information systems are being used at this time to support the treatment of MDD. A start has been made, however, in digitalising life charts, which ensures that information on mood swings can be more easily monitored and interpreted by the therapist and the patient himself.

2. Results of the chain analysis

The evaluation framework of the tenet of Chain-computerisation consists of four profiles with which the necessity and feasibility of a chain information system for a specific chain collaboration can be assessed. The advice for an information strategy is based on this.

The **mission profile** offers a description of the chain. Based on this, the necessity of a chain information system – at the level of the chain objective – is determined. The MDD chain-of-care is focused on the improvement of the quality of life for patients with a manic depressive disorder. The various chain partners must collaborate in order to be able to intervene in time and in balance. The dominant chain problem is, therefore: “intervention that is too late and unbalanced, because signals of approaching mood swings are difficult to interpret and are distorted – or get through too late or not at all.” The critical data that are essential for dealing with this dominant chain problem are: Citizen Service Number (BSN), indication of phase (manic/depressive), danger code, medication and a referral for the therapist. When this data is shared throughout the chain, it becomes possible to pass on

signals sooner and better and to limit the chance of escalation. According to this profile, a chain information system with the above-named critical data is essential in order to alert the consulting physician to a mood reversal more quickly so that the medication can be adjusted in time.

By using the **coordination profile,** it can be determined – at the process level – whether or not a chain information system is necessary for the chain-wide coordination in order to deal with the dominant chain problem "intervention that is too late and unbalanced, because signals of approaching mood swings are difficult to interpret and are distorted – or get through too late or not at all." The MDD chain-of-care is a complex one because the patient is in treatment continuously and, therefore, can be present in several places in the chain process simultaneously. For that reason, it is essential that involved parties and healthcare professionals are in tune with each other, with mutual adjustment requiring both feed-forward and feedback. This means that, according to the coordination profile for the MDD chain-of-care, a chain information system is essential for the purpose of the chain-wide coordination.

The **information profile** makes it possible to asses – at the level of the information-exchange itself – the necessity of a contemplated chain information system. For each step in the process, a core concept is defined that characterises the focus of the chain partners in that particular process step in the chain. Thus, in the process step 'information provision,' the focus is on the symptoms of MDD and, in the process step 'diagnosing' on the patient. These various focuses demarcate 'linguistic regions' in a chain that are independent of each other and that cause structural communication problems to be expected that cannot be glossed over by better organisation or good intentions, because the causes are inherent in the process. However, disturbing consequences can be prevented as well as possible with a chain information system.
These linguistic regions are visible in an information profile through the so-called fault lines. The information profile of the MDD chain-of-care shows a fault line between the process steps 'signalling' and 'diagnosing' and between the process steps 'treating' and 'observing.' There are, therefore, two different structural communication problems in this chain; one surrounds an early and accurate diagnosis and the other surrounds a swift signalling of mood changes during treatment. In order to bridge these fault lines and to remedy their most disturbing consequences, chain information systems are, therefore, essential in this chain.

The **co-operation profile** allows insight into the extent to which the parties in the chain are accustomed to certain forms of co-operation. Based on the degree of organisation of the chain, the feasibility of a chain information system can be determined. This degree of organisation is scale dependent: on the regional level, the co-operation can, for example, be further developed than on the national level. The degree of organisation in the MDD chain-of-care is, even at the local level, too low for successful chain computerisation. At the supportive level, patients are discussed, both formally and informally, but common decision making at this level is not reported. At the level of the primary process, there is formal consultation on specific patients between therapists (not all of them) at most, but often not with the other parties involved. There are national guidelines for the diagnosis and treatment, but locally, there is no structural co-operation on policy matters. This low degree of organisation makes even a local chain information system for the MDD chain-of-care unfeasible at this time.

3. Advice on information strategy

It appears from the chain analysis that, in the present situation, a chain information system is not feasible because of the low degree of organisation in the chain. Among the various chain parties, there is, indeed, a great deal of expertise available on the treatment and counselling of MDD patients. There are also national treatment guidelines, questionnaires and training courses available for therapists. This knowledge is, however, insufficiently shared and not collectively mobilised in the treatment of MDD patients. The various therapists are, moreover, insufficiently attuned to each other.

In order to still be able to structurally improve the quality of life of MDD patients in the long run, chain parties could best first focus on the further development of the chain co-operation, with two spearheads:

a. *The contact between the primary and secondary lines of care for MDD patients*.
   For an early diagnosis, better support for general practitioners is desirable. The patient often does not seek medical help during the manic phase. General practitioners have too few bipolar patients to be able to recognise the disease quickly and also have insufficient consultation time available for this category of patients. Perhaps, a specialised social-psychiatric nurse could organise a special instruction session for a number of general practitioners and, if necessary, could also initiate the communication between the first and the second line.
b. *The collaboration between the second line organisation and the private psychiatrists*.
   National guidelines for diagnosis and treatment are generally well adhered to within facilities, but among the self-employed psychiatrists, the compliance is minimal, in spite of possible disciplinary sanctioning.

In the future, a local chain information system that – according to the chain analysis is actually necessary – could possibly become feasible.

Moreover, in this chain, there are great gains to be achieved through – with the patient's consent – *structurally involving the MDD patient's environment in the treatment* with the objective to pass on to the therapist – as quickly as possible – signals that indicate a mood reversal. Those around the patient often see a mood reversal coming before the patient himself does. This information is essential for dealing with the dominant chain problem. If the signal is passed onto the therapist early – for example with the aid of a text message or e-mail – the patient can be prevented from ending up in an extreme mood situation. The Society for Manic Depressives and Their Families (VMDB) has a great deal of knowledge and experience in keeping those involved with the patient informed and involved. The use of this knowledge and experience could be an initial step in involving the environment more closely in the treatment.

4. Relevance for current Dutch IT projects for Public Health

In this section we explore whether the insights gained have potential impact on current or intended IT-projects that are relevant to this chain. Our focus at the national level is on the national Electronic Patient Record (EPR), the general umbrella under which work is being done on the large-scale computerisation of the healthcare system. This system is based on the local (electronic) patient files that are kept by medical professionals.

Under the umbrella of the national EPR, two pilot projects are in development: the Medical Files for the Doctor on Duty at that time (WDH[4]) and the Electronic

[4] Waarnemingsdossier Huisartsen (WDH) [Medical Files for the Doctor on Duty]

Medication Dossier (EMD). The WDH is, in principle, a local or regional provision; the EMD will become a national system. The MDD chain-of-care has been analysed here at the local level.

Medical Files for the Doctor on Duty (WDH)
The WDH contains – per patient – an extract with data which the family doctor feels are important for a substitute doctor. In view of the seriousness and complexity of the disease, the diagnosis of MDD, with the accompanying medication, should be part of this file. The patient records of general practitioners, self-employed psychiatrists, and psychiatrists within the Public Health system are at the base level of the MDD chain-of-care and are important for the feeding of a chain information system within this chain. The Medical Files for the Doctor on Duty, which are also at the base level of the chain, appear, initially, not to have any added value for the chain information system of the MDD chain-of-care.

Electronic Medication Dossier (EMD)
In the EMD system, a chain image is available – per patient – of important and permanent medication usage. We have a chain analysis of the medication chain[5] with another dominant chain problem: "the provision of medication that is dangerous to the patient due to lack of information on drug usage and personal risk factors." For that reason, we should expect that drug usage in connection with MDD, will ultimately be found in the national EMD system, along with other relevant medication and information on personal risk factors. This MDD chain-of-care analysis indicates, moreover, that drug usage is one of the critical items within the MDD chain-of-care. There is, therefore, a clear overlap between both chains, albeit in reference to a limited group of drugs in relation to personal risk factors. In the MDD chain-of-care, however, the dominant chain problem is: "intervention that is too late and unbalanced, because signals of approaching mood swings are difficult to interpret and are distorted – or get through too late or not at all." From this, it can be deduced that the chain-specific role of drug information in this chain is different than the one which must be taken into account in the general EMD system. This is chiefly about the speed with which the medication must be adjusted in order to prevent the treatment from getting out of hand, unnecessarily. This functionality is necessary for a limited number of patients only; the general, national EMD system is intended for all patients. Even in the long term, it cannot be expected that the national EMD system will be able to provide this fast signalling in a cost effective manner. It can, therefore, be concluded that the MDD chain-of-care should ultimately be able to have its own chain information system at its disposal because the general nation-wide EMD system will prove not to be sufficient. The MDD chain information system and the national EMD system should then be linked, certainly for MDD patients who also have other chronic diseases.

[5] Grijpink, J.H.A.M. & Plomp, M.G.A. (Eds.). (2009). *Kijk op ketens: Het Ketenlandschap van Nederland* [View on chains: The Chain Landscape of the Netherlands] (pp. 189-191). Den Haag: Centrum voor Keteninformatisering. ISBN 978-90-811470-2-6 (www.keteninformatisering.nl)

Appendix

Chain analysis Manic-Depressive Disorder Chain-of-care 2010

General information	
Source	Chain Landscape Research Programme (Utrecht University)
Date	March 2010
Scale	Local
Number of cases	There are 288.000 people with MDD. 100.000 qualify for treatment, but less than 50.000 are actually being treated. It takes an average of 10 years before a diagnosis is made (Bipolar disorder for patients and their families: A guideline – LithiumPlus Workgroup and VMDB).

Mission profile	
Social chain product	Health
Chain challenge	To improve the quality of life of patients with a manic-depressive disorder (MDD).
Dominant chain problem	Intervention that is too late and unbalanced, because signals of approaching mood swings are difficult to interpret and are distorted – or get through too late or not at all.
Target group	Persons with recurring extreme mood swings which hinder their ability to function.
Chain partners	Psychiatrists, crisis services, psychotherapists, the patient, immediate environment (family, friends, etc.), psychologists, family doctors, Public Health Services [GGD], Society for Manic Depressives and Their Families [Vereniging voor Manisch-Depressieven en Betrokkenen (VMDB)], doctors, pharmacies, social psychiatric nurses (SPV's), social workers, Foundation Labyrint~In Perspective, company doctors, Knowledge Centre for Bipolar Disorders [Kenniscentrum Bipolaire Stoornissen], GGZ [Public Mental Health] facilities, Trimbos Institute, Stanley Foundation, Ypsilon
Process steps at operational level (links in the chain)	1. Information provision: information on MDD. 2. Signalling: signalling of symptoms of MDD. 3. Diagnosing: diagnosing the disorder and the mood swings. 4. Treating: therapy for the treatment of MDD (generally making use of the so-called 'life chart' for keeping track of mood swings). 5. Observing: monitor the patient and, upon approaching 'turning points,' adjust the medication/treatment, if necessary, feedback to 'Diagnosing'.
Intermediary product(s) of each link	Early recognition (1), Suspected MDD patient (2), Treatment plan (3), Therapy (4), Signals (5)
Critical details	Citizen Service Number (CSN) [NL: Burgerservicenummer (BSN)], Indication of phase (manic/depressive), Danger Code, Medication, Referral to the therapist involved
Important points of contact	Environment (family/work), therapist, doctor

Criterion for the chain	Diagnosed MDD
Conclusion	A chain information system with the above critical data is essential for dealing with the dominant chain problem.

Coordination profile	
Coordination form	Standardisation of expertise
Reasoning	Because of training and information services, there is standardisation of expertise. Moreover, for both therapists and other chain partners involved, instruments are available (screeners, such as the MDQ, guidelines for bipolar disorders, life charts and emergency plans).
Process structure	Complex
Reasoning	A patient is treated continuously and, moreover, can be simultaneously present in several chain process steps. Therefore, it is essential that the chain partners involved adjust mutually with both feed-forward and feedback to be able to intervene in a timely and balanced way.
Conclusion	A chain information system is necessary.

Information profile				
	Key concepts			
Process steps	Symptom	Patient	Intervention	
Providing information	X			
Signalling	X			
Diagnosing		X		
Treating		X		
Observing	X		X	
Reasoning	There are two fault lines: between 'Signalling' and 'Diagnosing' and between 'Treating' and 'Observing'.			
Conclusion	A chain information system is necessary.			

Co-operation profile					
	Form of co-operation				
Level of the chain process	**Informal consul-tation**	**Formal consul-tation**	**Joint decision making**	**Chain project**	**Joint chain body**
Support	X	X			
Primary process	X	X			
Policy	X				

Reasoning	Care for bipolar patients is generally organised by the municipalities. Nationally, there is a bipolar knowledge network for policy development, but not for patient treatment. Locally, at the support level of the primary process of treating patients, there only are informal and formal consultations on specific patients between therapists (but not all of them). Generally, family doctors have too few patients with bipolar disorder to be able to recognise the disease and to be able to take part in the local consultation. Locally, there is no structural formal consultation on policy matters.
Conclusion	A chain information system is not feasible, even at the local level.

Registers	
National registers	Municipal Residents' Database [NL: Gemeentelijke Basisadministratie (GBA)]
Source registers	Medical dossiers
External registers (other, from other chains)	Citizen Service Number (CSN) [NL: Burgerservicenummer (BSN)]
Chain registers	-