

Diagnosing and acting upon dementia: the transformative power of the Marte Meo Method as therapeutic intervention and diagnostic instrument in dementia care

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Introduction

Over the last few years a new tool and method has been introduced in care for people with dementia in Norway: the Marte Meo method.¹ The method was developed in clinical psychology as a tool for improving communication between parents and infants but is now widely used also in schools and dementia care. It is a form of intervention or therapy that focuses on the interaction and communication between, for instance, people with dementia and their carers, and seeks to strengthen the relational and communicative competence of carers in order to facilitate better interaction and better care. As such it is an indirect intervention in that it is the carers that via videoimages and guidance are helped to see the patient and the problem in new ways, and to act to support them better. 'Marte Meo' means 'of one's own force' or 'power', and the aim of the method is to support the needs and competences of the patient – by strengthening the human relations of care.

At the centre of this method stand video recordings of sequences of interaction, and guidance on the basis of these filmshots. A Marte Meo therapist records (problematic) everyday interactional situations, such as meals, washing, brushing of teeth, wandering, fear/pain, or aggressive behaviour, and then analyses the interaction in slow motion, with a focus on moments of good contact and interaction. The therapist presents sequences of these recordings in meetings with the carers involved with the particular patient. The carers are invited to analyse and discuss what they see, and learn to see both the patient, themselves and care relations in new ways. Glimpses of contact and positive moments are then used as the building blocks of a solution. Collectively, a shared way of meeting and handling problematic activities is laid down.

As said, the method is meant to contribute to the human relations of care. In my paper for this workshop, however, I want to lay out and analyse in detail some of these uses of the Marte Meo instrument to see *what more* it does than care about human relations.

The Marte Meo method in practice

I am sitting in on a meeting with carers on a sheltered ward for people with dementia in nursing home Y. We are in one of the living rooms and are seated in a half-circle fronting a television and video machine. The purpose of the meeting is guidance, or supervision, with a Marte Meo therapist, who happens to be the head nurse on this ward. The occasion is a new, or relatively new, patient, Mr. X, who makes a so-called 'problematic case'. The carers are afraid of him, and he is the kind of patient that wears everyone out and draws all the attention and energy on the ward upon himself.

As said, Mr. X is a relatively new patient in nursing home Y. Before this, he has had a long history of moving between different institutions for elderly and dementia care. No one seems to be able to handle him. He has been in and out of specialist health care for diagnosis and evaluation, but has not so far received a longterm place in an institution for psychiatric geriatrics. His diagnosis is dementia with additional psychiatric conditions. He is said to be aggressive, 'out-acting'/ agitated, restless, showing compulsory behaviour, and even suicidal. He lies on the floor much of the time, crawls under the sofa or table, screams and howls, but has no recognisable verbal language. He is of vietnamese origin, which makes the communication and interaction even more difficult, since there is a foreign language problem on top of the other challenges associated with dementia. Having learned Norwegian only later in life, this is also the language that gets lost first in the course of living with dementia. Mr. X does not sleep much during night or for long hours during day either.

Having taken Mr. X in as a patient and seen the challenges and problems, the head nurse and medical staff decided to try the Marte Meo Method.² Along with this, they map and document his condition with a so-called 24-hour-scheme. The folder documenting his condition over the past weeks is present on the table between us in this meeting. On a first quick glance it makes a booklet rich of colours, sheets covered with mosaics of pink, green and black, indicating restlessness, compulsory behaviour, aggression, and awakens. But also a positive development: there is more and more yellow and less and less black, pink and green...

So what have they done? What are they doing? How does the Marte Meo therapy work?

In the meeting we are presented with an edited version of the video recording of an interaction where a nurse is trying to get in contact with Mr. X who is lying on the floor and

screaming. She kneels down at his side, touches him with her hand on his shoulder and bends over him to try to get eye-contact. She calls his name.

The therapist, i.e. the head nurse, uses the remote control actively to stop, hold still, rewind, repeat, and run the film in slow motion while analysing, or rather presenting and discussing her (prepared) analysis, with the carers in the circle. The nurses are however also invited to take part in the analysis through questions such as: What happens here? What does his face or bodily gesture express? Where is his focus or energy – where or what is it directed at? What is his need or concern? In this moment of good contact, what facilitated it? What did the carer do, or what in the interaction contributed to it?

We return to the film. Another sequence: the nurse asks Mr. X if he would like to get up from the floor. She takes his hand. She awaits his reaction and then helps and draws him up in a sitting position. Mr. X lifts his hand and arm, and the carer moves back, withdraws, anxiously – is he going to hit her? But he is not – and while she is staying calm, he pats her on her head and gently strikes her hair.

More analysis: what goes on here? How does the nurse keep in contact and hold him in – through touch, body positioning, face- and eye-contact, but also naming, explaining and acknowledging the action and interaction...? What about the pace or tempo and intensity of interaction? Then an initiative of action on his part: a nervous moment. But what is it about the rhythm of interaction, or ‘dialogue’, of shifting between action and reaction, that changes here? And what does it do for Mr. X?

More film and interaction: It takes time, and there is not time to elaborate this here, but in the end the nurse and Mr. X are sitting next to each other in the sofa. The nurse is still holding Mr. X’ hand, and also holding an arm around Mr. X’ shoulder. Mr. X legs and feet are running nervously like drum sticks, but he is sitting calm with her and he is smiling at her.

For some months now, the institution Y has worked repeatedly with new sequences of videorecording and with guidance through collective engagement with these videoshots. The results are quite amazing. The bunch of 24-hour-schemes show a remarkable change. Where there was before red, green and black, there is now more and more yellow – and Mr. X is more and more happy and content, calm, relaxed and sleeping during night, no longer aggressive and almost rid of his compulsory behaviour.

The staff has also done research on Mr. X’ history and background and learned that he was a mechanic and used to run a car repair shop. The nurses interpret his so-called compulsory behaviours – lying on his back on the floor and crawling under sofas and tables – as having to do with this history: he is used to lying under cars. The head nurse got hold of

some small tools, children's copies of tools, and Mr. X likes to sit – and sometimes still also to lie on the floor -- and fiddle with them.

The transformative power of the Marte Meo method

What I want to use this story to argue, is, first, the transformative power of the Marte Meo method as a therapeutic intervention in dementia care. Indeed, once introduced, this instrument carries the potential to challenge and transform the notion of dementia itself with its biomedical underpinnings. Behaviours that used to be attributed to the disease as a separate agent, and to the brain internal, degenerative processes and conditions it sets going, here suddenly emerge as more social, collective or interactional phenomena. What used to be understood as objective realities with ruthless consequences for but otherwise separate from and inaccessible to the person and everyday life, to be treated by pharmacological means, here come out as socio(technical)biological conditions that can be treated and in some circumstances at least even 'cured' by interactional means.

This becomes manifest for instance in nurses' talk of the necessity of tuning in on the frequency of the person with dementia in order to be able to hear and see her signals, her reaction, initiatives and attempts at communication. These are seen to be weaker and more difficult to interpret, but also requiring adjustment of tempo (i.e. slowing down!) and intensity on behalf of the carer. It is also evident in statements by nurses such as "We have verbal language as our tool to take control of incomprehensible matters. People with dementia do not. But even if a person has dementia this does not mean that it is empty in there. You just have to find her language." And: "They have not sailed off and totally disappeared into the darkness. Their emotional life is still there even if their brain is impaired."³

This is not like biomedicine. It is a different way of understanding and enacting and working on dementia. The nurses here argue that though people with dementia may not have verbal language, this does not mean that they have disappeared into a 'mist of oblivion', or some unknown land, that they have left real life reality, and that they have got lost to us before they have actually left us. That they are 'living dead' and that there is simply 'no one there'. That patients with dementia lose – or are deprived – of their mind, their rationality, and, by implication, their subjectivity, personhood, and dignity. The nurses involved in Marte Meo therapy contest and challenge such widespread ideas and tropes both in practice and in theory. People with dementia are not irrational or a-rational beings. Instead we need to find and understand their language, their signs and signals. A matter of relating – and a different way of relating – in which subjectivity and dignity emerge, yes, relationally.

What these nurses are involved in, I want to argue, is the articulation of an alternative version of dementia – together with an alternative form of subjectivity or personhood. On the one hand, the causal links between biochemical changes in the brain, erosion of intellectual, communicative and social capacities, and eradication of subjectivity, dignity and humanness, postulated by the central dogma of the biomedical approach to dementia, are contested and broken. Subjectivity is much more and other than intellectual capacity, and does not necessarily go or get swept along in the undertow with biochemical and or neurodegenerative processes in the brain. On the other hand, both the dementia /disease and subjectivity are placed in a much wider set of relations. No longer seen to be simply brain-internal matters, they are set in the relations of the person and her everyday life. The reality of dementia thus becomes both objective and relational. It is something you are both confronted with and something that can, within limits, be accessed and shaped. It is object and relation, and the object is made in and through relations. When the nurses work on the relations of the dementia, they also transform the object. For instance, if they slow down the interaction and communication, the person with dementia may be able to act and react, take turns in dialogue and interaction, and so participate competently. But if the nurses do not take the time to wait for a response and move on to new themes and questions or to new patients before the person with dementia has time to respond, this leads to misunderstanding, frustration and aggression.

Accordingly, by manipulating and working on the relations and practices of care the nurses reconfigure subjectivity and then redistribute it – with the effect that people with dementia also come out as active, rational, conscious, communicative, emotional and capable. They emerge as full of life rather than its opposite.

According to the advocates of Marte Meo, this method cares primarily about the nature and quality of the human relations with people with dementia. As one of them put it: “the disease is chronic, there is today no cure for it and it progressively gets worse. The most important treatment measure we have today is therefore human relations”. But what the above shows, is that Marte Meo (at least potentially) cares about much more than strictly speaking human relations and communication. Indeed, it is my claim that Marte Meo also cares about and contributes to the nature/definition of the disease, as well as the widely distributed and heterogeneously material character of ‘the human’, ‘the relational’, and ‘the dementia’. I will return to this later.

The entanglement of diagnosis and intervention

The next point I want to make is about the entanglement of diagnosis and intervention. What the above shows, is that diagnosis and intervention are intertwined, not separate and sequential. There is not diagnosis first, then intervention, then evaluation, or medical knowledge and practice first, and then care. What we see and have is rather diagnosis as tinkering and ongoing process, and diagnosis emerging through engagement and intervention.

Mr. X came to nursing home Y with diagnosis and pharmacological treatment. As this treatment was not seen to be adequate or appropriate, new interventions were implemented and tested out. By way of the Marte Meo method and instrument the staff identified, tested out and agreed upon ways of meeting and interacting with the patient. These interventions then changed the understanding of the problem, the case, and diagnosis and definition of the disease, too. The problematic, nervous, agitative and aggressive behaviour is no longer understood as belonging to and caused by the specific form of brainorganic, or neurodegenerative, disease Mr. X is said to suffer from, but as largely provoked and produced by the nature and quality of the interaction and communication that Mr. X is involved in. These deprive him of the possibility of understanding what goes on and participating. They deprive him of the possibility of taking up positions as subject, as speaker, and as active agent making initiatives and taking turns in social exchange and communication. They deprive him of bodily contact and tenderness. Similarly, the compulsory behaviour is reinterpreted as embodied practice, as a form of familiar action and perhaps even communication in a world that has become scarily unfamiliar and inaccessible.

Other cases with patients suffering from fear and or pain, and so problems for instance with situations of washing and dressing, also demonstrate the same entanglement of intervention and diagnosis:

Mrs. Z is a frail and almost bedridden old lady on the same sheltered ward for patients with dementia as Mr. X. She always cries when the nurses try to wash and groom her, but it is difficult to know whether the reason is fear, pain, or both. The verbal communication of Mrs. Z is very limited and she cannot herself report upon or explain her uneasiness. Again, the interaction – this time the morning toilet /washing -- is recorded, analysed and discussed. It becomes clear that Mrs. Z has pain, but that the fear of pain also adds to the nuisance. However, while trying to avoid movements that hurt and frighten the patient, the nurses in performing the routine tasks of the morning toilet still don't see or recognise the pain. Only in watching themselves interacting with the patient on video, it becomes shockingly evident what goes on. The filmshots – the displaced, objectified, repeatable, still-pictures and slow-

motion pictures -- thus enable carers to see and listen and sense and read patients' verbal and non-verbal signs in new ways.

In a larger study of pain in patients with dementia and its diagnosis, also undertaken in nursing home Y, elements of the Marte Meo method have again been adopted.⁴ The study uses video recording of body movement in natural, everyday situations and practices such as washing, dressing and getting up to analyse and document pain, and pain experience, in patients with dementia. While the literatures claim that patients with dementia don't experience pain in the same way as patients without dementia, and so that people with dementia have a higher threshold regarding pain,⁵ this study argues that patients with dementia do experience pain in the same way as other people do, but lack the means to express and communicate it. The use of particular medications, such as neuroleptics, also adds to the difficulties with self-reporting and communication. But the videoshots show patients crawling up in the lie of the foetus after having had their arms stretched out in an exercise of washing and dressing. Pain is highly underdiagnosed in patients with dementia, the study concludes. The objective of this research project is to develop an instrument, a manual, for examining and diagnosing pain in patients with dementia.

Again it is clear that diagnosis is entangled with and emerges with engagement and intervention, as a result thereof and not in advance of it. New diagnostic tools imply both interventions and therapeutic methods and tools.

<<The performativity of diagnosis

That diagnosis is performative, not representative and interpretative only, and how different diagnosis/interventions performs dementia differently... that diagnosis is performative rather than representational, and so mattering, in several senses of the word. >>

Care as involved and implied in medical expertise and technology

Although caring with Marte Meo, as argued here, is not like biomedicine but a different way of understanding and enacting and working on dementia, it should still not be concluded that care is other, opposed to or inconsistent with object(ive) knowledge, expertise and technology. That first we have medicine, with systematic knowledge and documentation, research based evidence, and objectivising practice, then we have care – which is devoid of tools, instruments, methods and knowledge and comes down to doing 'almost nothing' -- but

offering some TLC- tender loving care. That biomedicine is simply about objects (objective realities) while caring is about (human) relations. Again, practice, and ethnography, reveal that this is not the case. What I argue here is that care is both involving, involved in and contributing to diagnosis, medical knowledge, systematic documentation and technology.

First, as we have seen and I have argued already, also in caring, dementia is both objective reality and relational, something you are confronted with and something that can, within limits, be shaped. Further, as with (bio)medical versions of dementia, the care version is also enacted and worked upon in specific material practices and arrangements. These include videorecording, analysis, experimenting with objects, relations and interactions, and manipulating these in typically problematic situations. Interventions and effects are mapped, documented and surveilled over time. But the objects and relations targeted here are not the same as those of (bio)medicine. Neither, too, are the framing assumptions about what makes a person, or the character of subjectivity. Ideas about where those capacities reside, how they are expressed or done, and how this is affected by the introduction of a disease like dementia are also different.

But the Marte Meo version is not just different. It is enacted explicitly as a difference, and alternative, to the reality of biomedicine, and perhaps especially that of the pharmaceutical industry. It says that there is no simple answer or solution, no easy pills to be taken, but there are still things that can be done. Although dementia is undeniably a reality with which patients and carers are confronted, it is also something that can be shaped within limits.

¹ The method was developed by Maria Aarts in the Netherlands about 25 years ago. Refs.

² Check about medication – probably somewhat cut down, as nursing home Y is characterised by the philosophy that there is generally a large overmedication in elderly and dementia care at the same time as many medications don't work, work/are processed less well, or create new complications, as many patients have far too many conditions and medications that in combination create more problems (people in nursing homes have many and complex conditions. On average, they are treated with 6-8 different medications. The figures are from Norwegian studies.). There is what is called a problem of 'co-morbidity'.

³ These statements are from presentations from the Marte Meo and dementia days 2004, NKS Olaviken Behandlingscenter, Bergen.

⁴ Bettina Sandgathe Husebø...

⁵ refs