

“It’s all in your head”: Magic and Misdirection in Medicine

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Abstract

In this contribution, we examine three stories of beneficent deception in medicine: the placebo machine invites children with treatment-resistant disorders to enter a high-tech machine and let their brains heal themselves; dementia villages extend validation therapy to the lived environment of geriatric care, supporting the illusion of living in the past through architecture; provocative testing relies on tricking patients suspected of fakery into experiencing seizures so that they can receive an expedited diagnosis. Enlisting the concept of misdirection from the realm of magic and theoretical contributions related to ‘stories’ and ‘storying practices’ from Feminist Science and Technologies Studies, we ask of each: Who is being deceived? Which ‘characters’ are given voice when these stories are told? How is deception justified? Following this, we question the onto-epistemological assumptions of reality and causation underlying each story and offer concluding thoughts on how ‘magic’ could be embraced within medical practice and research.

Keywords: misdirection, knowledge practices, clinical care, deception, placebo, clinical care

Introduction

Despite the adoption of autonomy as the central ethical tenet in Western medicine, deception remains ever-present across medical research and practice. Sometimes such deception is explicit, and at other times it takes on subtler forms. Discussions of such deception often examine the consequences and wrongs inherent in deception, but fail to consider the assumptions that loom behind its use. In fact, the instances in which deception is utilized, including the forms it takes, the patients that are deceived, and the justifications offered, can be remarkably revealing.

In this contribution, we examine three stories of *beneficent deception* in medicine, asking how the narratives that emerge around them operate to control the visual field and justify deception. Each case involves clear deception, in the form of lying or encouraging false beliefs in patients, and yet promises to outweigh the wrong or harm of such deception with clinical benefits. In the placebo machine, children with treatment-resistant disorders are invited to enter a high-tech, but ‘inactive’ machine and let their brains heal themselves. In dementia villages, validation



therapy is extended to the lived environment of geriatric care, supporting the illusion of living in the past through architecture. In provocative testing, patients suspected of fakery are tricked into experiencing seizures so that they can receive an expedited diagnosis.

On the face of it, each case involves an ethical wrong (deception) and an ethical benefit (beneficence) suggesting that the moral equation merely involves weighing the two against each other. Indeed, as will be shown below, this is how most ethical analyses of these cases proceed. However, behind the explicit deception seen in each case, *misdirection* is looming. Borrowed from the realm of magic, including emerging scholarship on the science of magic, misdirection can be understood as the intentional deflection of attention for the purpose of disguise" (Sharpe, 1988; Kuhn et al., 2014). As such, while misdirection may involve, or lead to, deception, it is primarily a form of distraction, leading one away from truth without necessarily denying it.

In taking up these three stories of beneficent deception through the lens of misdirection and feminist science and technology studies (F/STS), we aim to complicate the common moral equation, inviting analysis beyond the weighing of ethical principles and engaging the question of how misdirection operates in the way these stories are told. The realm of magic and the concept of misdirection can help to reveal how agency, acting, and story-telling are often veiled in medical stories of deception. Instead, stories of medical practice and research are often naturalized, made out to be the inevitable consequences of an objective expertise. At first glance, some medical feats may look like magic (she's healed!). But upon closer inspection, it is revealed that it is in fact the 'brilliance' of scientists and doctors behind the scenes who have learned their way around the human body, producing miracles of healing. As with magicians, doctors are praised for their ability to control and astound an audience, thus justifying a little trickery. Here, we question this narrative of magical, benevolent manipulation. Examining such healing as the result of a more *distributed agency* among various characters and components, we wonder if there might be an altogether different kind of magic at play.

This magic is not merely found in the advances of science, but is clearly co-made, 'configured' through an assemblage of actors. Noting this, we examine the real, but unrecognized, consequences (material, ontological, epistemological) that medical and research practices incorporating benevolent, and therefore acceptable/justifiable, trickery, can have on patients.

More importantly perhaps, we wonder about the *storying aspect* of these practices. In her work, Donna J. Haraway insists on the role of stories, storying, and narratives in the production of scientific and medical knowledge (Haraway, 1989; Haraway, 1996). Stories and story-telling, she argues, are an inherent and dominant feature of the production of knowledge. The concept of 'story' in scientific and medical practices allows her to reveal that these practices are always *partial tellings*, 'framings', told from particular perspectives (e.g. socio-historical, cultural, gendered, racial, classed) and inherently social, political, cultural, etc. This partial knowledge, derived from stories, shapes both ontological and epistemological assumptions, and informs how scientists view and act in the world, and the subsequent stories that can be told or not and on which one can act or not. Put otherwise: such stories have various consequences that are at once material and discursive.

Philosophers of science and scholars of Science and Technology Studies (STS), particularly feminist ones, who embrace the *ontological turn* in the sciences¹, document how scientific knowledge production is performative, in that it participates in shaping the objects of knowledge rather than simply discovering them and representing their 'essences'; (Pickering, 2017; Woolgar and Lezaun, 2015; Åsberg, 2010). In this new ontology, sciences 'work' (they produce knowledge) because they intervene in a real that is dynamic. They are only and always *interventions*, i.e. active practices that 'know' by participating/affecting the ongoing configuration of a world-as-becoming, in-an-ever-making (Alaimo and Hekman, 2008; Barad, 2007). Furthermore, they are intervening in a real that is not fixed, and therefore available to representations, but dynamic, always changing, in the process of 'being-made', but where the 'materiality' of matter warrants careful attention because these

transformations can never be erased, but only responded to. They can change again, but not in an infinite number of ways. This recognition that the sciences are actors in shaping our world (and thus making ontological and ethical changes), however, remains marginal at best. Epistemically, knowledge practices continue to be practised as if pure objectivity, neutrality, and distance can be achieved.

In this contribution, we invite these insights emerging from F/STS into the realm of medicine and health research with a particular focus on uses of *beneficent deception*. Our methods involve a detailed analysis of three examples of beneficent deception in medicine, particularly of the ‘story-ing’ they enact, we examine how these stories are told, what assumptions underlie them, and how they misdirect audiences, both those directly involved and those at a distance. We utilize a variety of texts to represent these stories, including academic publications from medical researchers, clinicians, bioethicists, and social scientists, as well as narratives found in the media. These texts offer a glimpse into the ways these stories are told by those who have the most control over the narratives that circulate around placebo machines, dementia villages, and provocative testing, leaving space for our analysis, which utilizes both the analytic of misdirection and the tools of F/STS.

In light of each story, we ask: Who is deceived within the stories? Which characters are given voice when these stories are told? How is deception justified in these stories? With our own analysis, undeniably, we, too, are telling/creating stories – but other ones, and perhaps ones that are – we hope! – more positive, ethical, *freeing*. Hence, echoing Haraway and embracing her proposal regarding the role of stories and storying in science, we propose our analysis as a way to *enable storying*, that is, to create an occasion for more stories about these cases to be told and, perhaps, to permit new configurations. With this analysis in hand, we suggest that there is great potential laying within the tools of ‘magic’, including magical misdirection, but that how such magic is currently used and framed in medicine restricts this potential from emerging².

Three Stories

The Placebo Machine

Experimenter: You know when you’re playing outside and you get a scratch on your hand? What happens to it?

Participant: It heals.

E: And what do you have to do to make it heal?

P: It just heals on its own.

E: That’s right. The body heals on its own—you don’t have to do anything. That’s what we study.

Just as your body knows how to heal itself, your brain knows how to heal itself as well.

(Olson et al., 2021: 3)

The placebo machine was dreamt up by Jay Olson, a magician and placebo researcher, whose first magic show took place when he was 7 years old, and Samuel Vessière, an anthropologist and cognitive scientist with a diverse research program (Haldane, 2019). The research project, described in detail in the paper “Super placebos: A feasibility study combining contextual factors to promote placebo effects” published in *Frontiers in Psychiatry*, brought together lessons they had learned both from the science of magic and the science of placebos. Eleven children with various treatment-resistant conditions (e.g., Attention Deficit/Hyperactivity Disorder, Tourette Syndromes, migraines, skin picking) were recruited to take part in the study. Before encountering the placebo machine in person, children were shown a video of celebrities talking about the special opportunity those recruited to the study had to experience a machine that can help the brain heal itself. A month later, participants were invited to the lab, where they first met with the researchers, who were dressed in lab coats, a science communicator, and a camera crew from Los Angeles there to document the “novel procedure” (Olson et al., 2021: 3).

First, children were briefed, reminded that the procedure will help their brain heal itself and told by another child (a ‘peer mentor’) about how well it had worked for him (Olson et al., 2021). Then, a 15 minute interview took place where the children were encouraged to focus on their strengths and build positive expectations about their experience with the placebo machine. Finally, participants were taken into the scanner room, where an

impressive (but inactive) MRI (Magnetic Resonance Imaging) machine stood, accompanied by “space music” (Olson et al., 2021: 3). Children entered the scanner for 15 minutes; while inside, they were encouraged to focus on the “mental superpower” they want to develop and given suggestions like “As you slide deeper into the machine, you will find yourself feeling more and more relaxed and focused” (Olson et al., 2021: 5). Positive suggestions were again given after the scan and each child took home a watch that would buzz periodically and show a positive icon like a smiley face. Each participant came back a week or two later for another “sham MRI session” and then again for an exit interview. Follow up found that “ten of the eleven parents reported improvements in their children following the sessions. Two children showed near-complete cessation of symptoms” (Olson et al., 2021: 5).

Dementia Villages

“It’s a little bit Disneyland, a little bit Las Vegas and a lot more fun for residents than a sterile nursing home.”
(Rogers, 2018)

In his contribution to the anthology *Care home stories: Aging, disability, and long-term residential care*, Alzheimer’s expert Peter Whitehouse describes the increasing trend in long term care towards helping people with dementia to feel more at home “by allowing them to bring personal furniture and mementos when they moved in” (Whitehouse, 2017: 106). While he is supportive of this trend in general, Whitehouse notes that one facility he visited, a *dementia village*, “took this attitude to such an extreme”, noting that the “unreal reality” he encountered there made him feel uncomfortable (Whitehouse, 2017: 107).

Dementia villages refer to an emerging architectural design for long-term geriatric care facilities and represent a social approach to caring for the elderly who are experiencing cognitive decline and dementia. These villages extend validation therapy from words and actions to the lived environment: “the facility creates an environment that is designed to mask the dementia by pretending that the residents are in an earlier time and place” (Whitehouse, 2017: 107). Residents

in dementia villages are validated not only in their interactions with caregivers (dressed up as postal workers or grocery store clerks), but in the buildings, the furniture, the posters on the walls. Seen as an optimal design to foster, maintain, and promote autonomy as well as independent living for the person experiencing dementia, geriatric facilities are designed as villages, often from another time (e.g. 1950s or 1960s), and decorated as if they were local and pedestrian ‘village hubs’. Describing his visit to De Hogeweyk, the first dementia village, built in the Netherlands in 2009, Whitehouse notes that the units “were designed to match various forms of Dutch social life (one even mimicked Indonesia for those who immigrated to the Netherlands from the former colony)” (Whitehouse, 2017: 107).

Since the opening of De Hogeweyk (also known as Dementiaville) the model has spread to the United States, Canada, the UK, and Japan (Biggs and Carr, 2016; Iakovou et al., 2019). Echoing the grand hotels of Las Vegas and the rides of Disneyland, dementia villages use the art of simulacra while suggesting that geriatric care need not be cold or a source of further trauma, but can be made into a pleasant, even dreamy, experience where those who have cognitive decline can reminisce about their past and be validated by their surroundings. Often compared to the Truman show, corridors in dementia villages are often decorated to mimick outdoor pedestrian streets and alleys, residential rooms’ doors are painted as if they were individual homes, and flowerbeds, false windows, and benches decorate common areas. Aimed to both provide comforting and familiar homes for residents, that also recall and even re-enact aspects of their past, dementia villages hypothetically facilitate the agency of people with dementia. Despite these good intentions, Whitehouse wonders if perhaps we might be better off with efforts to support people with dementia to “navigate their own ‘real’ community”, engaging in a form of “playful reminiscence” rather than the “serious fakery” entailed by dementia villages (Whitehouse, 2017: 107).

Provocative Testing

The goal of distinguishing between patients who are telling the truth and patients who are faking it

has a long history in Western medicine (Goldberg, 2021). In many such cases, telling the truth is shorthand for symptoms for which a physical cause can be identified, while faking it is a stand-in for unknown or psychological causation. Provocative testing involves using deception in order to diagnose psychogenic non-epileptic seizures (PNES) (also known as pseudoseizures, or spells), seizures that are not caused by epilepsy and are thought to be psychological in origin. In his bioethical analysis of the topic, James Bernat introduces us to Ms. Lamonica, a 38 year old patient, 'in good health except for being overweight', who presents for a neurological evaluations after experiencing at least two seizures (Bernat, 2010). During these seizures, she was awake and did not display any confusion afterwards, which leads her neurologists to "suspect that her episodes were nonepileptic seizures" (Bernat, 2010: 854). The chief neurologist decides to use *provocative testing* to confirm this suspicion, so the nature of Ms. Lamonica's seizures can be uncovered, and quickly.

To this effect, Ms. Lamonica first has EEG electrodes attached to her scalp and an intravenous catheter inserted (Bernat, 2010). She is informed that a solution that typically provokes a seizure will be administered. This is, however, false. The solution is simple saline, a pharmacologically inactive substance which acts as a placebo, generating negative expectations and provoking a seizure in some patients³. Ms. Lamonica is told that if a seizure occurs, the administration will stop, and, consequently, the seizure. If the EEG reading is normal throughout the seizure, it is concluded that the placebo effect, operating through negative expectations, caused the seizure, not the substance. In such cases, the patient is 'caught out' and the psychological nature of the seizures revealed. The neurologist will then likely refer the patient to a psychiatrist. This was the case for Ms. Lamonica, who had a seizure after the saline administration while her EEG recording remained normal. Afterwards, we are told, the neurologist "wrestled with the question of whether to tell Ms. Lamonica that the provocative test had been a ruse" (Bernat, 2010: 855).

Telling these stories otherwise: It matters how stories are told

As Haraway points out, "it matters whose stories tell stories" and stories *matter* (Haraway, 2019: 565). How stories are told and by whom have multiple effects, many of which are not or cannot be known, and are often not considered. Furthermore, stories are also never the sole domain of the *discursive*; they incur *material* effects and they also are *performative*. In this section, we examine the telling of these stories in greater detail. We ask: Who is deceived within the stories? Which characters are given voice when these stories are told? How is deception justified? Through our analysis, several forms of misdirection come to light. We reveal how these stories do not merely describe the world, in an objective fashion, but select certain characters, create particular narrative arcs, and point towards specific arguments. In doing so, other characters are hidden, different narratives become invisible, and some arguments slide out of view. As such, these tellings constitute an ongoing and surreptitious form of misdirection, one that is not always intended or even known to those doing the telling; and all have various, *material* consequences, that should not be sidelined.

Crucially, through our analysis of these stories and the misdirection contained therein, we are telling new stories. In doing so, we hope to reveal the way in which all of these stories, those we analyze and those we produce, are partial and limited. In constructing alternative stories, however, we aim to show that it is possible to *open up* to more productive uncertainty in medical practices and research. These new stories, we hope, may open up more onto-ethical medical practices, favoring relationships, and fostering new knowledge of health, illness, and healing. Current 'framings' and stories can reinforce simplistic and ultimately dangerous notions of reality and causation in biomedicine, that warrant a reckoning. As a result, we also advocate an *ethic of response-ability* in taking up magic in medicine.

Who is deceived within in these stories?

In each of these tellings, some characters take on the role of the 'magician', doling out deception, while others constitute 'audience members', on

whom the trick is played. It is noteworthy who is selected for each role. Magicians, those who are in control and writing the script, generating the experience for others, are played by the experts in each scene. In the placebo machine experiment, researchers take up the task of creating an illusion of neuroenchantment for participants (Ali et al., 2014). In dementia villages, architects, health professionals, and orderlies, all engage in daily deception to produce a novel 'reality' for residents. In the clinical practice of provocative testing, doctors attempt to trick patients into experiencing pseudo-seizures, to determine if those seizures are *really real*. Audience members are on the receiving end of the 'entertainment', unaware of what is taking place behind the scene and uninvolved, construed as both passive and active: they participate in the action, the 'doing', but unknowingly and unintentionally, while following along, *somewhat* willingly. The choice of which patients are to be deceived in each story is revealing; these characters and their descriptions invite paternalism, welcomed in the name of benevolence, thus misdirecting readers away from their agency and towards the importance of others acting in their best interest.

Placebo Machine

Lying to children is widely accepted, from Santa Claus and the Easter Bunny, to where a dog goes after it dies, to whether a dish contains broccoli. Paternalism, in the form of deciding for children, is also commonplace: what they eat, where they go to school, and where they live, are all choices frequently made by others for their wellbeing. Children are construed as imaginative, playful, and trustworthy, making them ideal audience members for a magic trick. The placebo effect is a particular kind of medical 'magic' that many argue is real and powerful yet has not been exploited enough (Benedetti, 2009; Miller et al., 2013). To perform such magic, children constitute ideal participants given the desire of many of them to play along and to please. Interest in placebo effects in children is longstanding and suggests there may be an increased power of placebos in those who have yet to grow into skeptical adults (Weimer et al., 2013). However, some placebo scholars raise questions about whether these documented

placebo effects exist in the children themselves or whether they might be better understood as instances of 'placebo by proxy', where hopeful parents and teachers report positive changes in a child's behavior, driven by their external expectations (Whalley and Hyland, 2013; Waschbusch et al., 2009).

In the context of the placebo machine, the children selected to participate are especially good contenders because they have a hodgepodge of conditions (e.g. ADHD, Tourette Syndromes, migraines, skin picking) found to be responsive to placebo treatments (Olson et al., 2021). The participants had also "already undergone conventional treatments with little or no effect" (Haldane, 2019). Because of this, ethically dubious interventions, such as those involving deception, are more likely to be accepted: there is little available for these patients. Such interventions may be seen as 'better than nothing', since the medical apparatus has often, in a sense, given up on them. In some cases, this desperation can boost the expectations of parents and children alike, contributing to increased placebo effects. Yet in other cases, they may feel hopeless, as nothing has worked, generating nocebo effects instead.

Dementia Villages

In dementia villages, those on the receiving end of the deception are also unlikely to raise significant concerns, given the preponderance of deception that already exists in their care. Practices, attitudes, and guidelines regarding deception are frequently discussed in literature related to the care of individuals living with dementia (Tuckett, 2012; Cantone et al., 2019; James et al., 2006). Validation therapy offers an example of such a focus, suggesting that rather than fighting against or repeatedly correcting the beliefs and impressions of those with dementia, we ought to validate them. As one therapist working with patients with dementia put it, "It's much better to validate with them and let them think what's in their mind is real than to disillusion them. They are happier in their little world" (Tuckett, 2012). Given the normalized uses of deception in dementia care, a little more blurring of the truth may be viewed as harmless.

Playfulness and deception also often go hand in hand. One nurse describes her approach to care of dementia patients: "I bullshit with those residents who are not in reality. You play along with them, those with dementia" (Tuckett, 2012: 13). The notion of playing with patients highlights the parallels between how patients with dementia and children are seen. As with children, the autonomy of patients with dementia is often considered non-representative or inexpressible, and so is often overruled or not considered. Dementia patients are also often compared with children or described as exhibiting 'childlike behavior'. In describing the results of qualitative interviews with family members of people living with dementia, the authors noted that childlike behaviors were often used, including "playing with soft toys, mimicking a child's voice or playing and running about" (Tyrrell et al., 2020: 6).

Provocative Testing

Who is most likely to be subjected to the trickery of provocative testing? Because infusing saline along with a placebo expectation aims to catch a patient in the act of fakery, it is unsurprising that those implicated in this 'magic show' are those who tend to raise the most suspicion amongst health care professionals. Takasaki and colleagues remark that there is a "preponderance in adolescent females" in the population that suffers from PNES (Takasaki et al., 2016: 4). These patients are often reported to have "dramatic, emotional, and erratic" personalities, igniting stereotypes of teenage girls and attention-seeking performances (Takasaki et al., 2016: 4). What's more, these patients often have psychiatric comorbidities, especially in children and adolescents diagnosed with psychogenic seizures, 84% and 49% of whom respectively have also been given a psychiatric diagnosis (Takasaki et al., 2016). In adult patients, personality disorders appear to be common in patients diagnosed with PNES, particularly those associated with cluster B, which are often linked to histories of sexual abuse from a trusted other (family member or friend) (Takasaki et al., 2016; Kanner et al., 2012; Devinsky et al., 2011; Bernat, 2010). Those diagnosed with such personality disorders are among the most despised and disparaged of patients in health care. "Derogatory

and cynical" jokes about patients with borderline personality disorder are common in medical schools, while clinicians often see such patients as not suffering from a 'real' illness, blame them for their own suffering, and view them as a drain of medical resources (Kealy and Ogrodniczuk, 2010; Wear et al., 2009).

Unsurprisingly, patients are aware of their suspicious status within clinical settings. In qualitative interviews with patients diagnosed with PNES, a common theme across patients has been "a perceived lack of understanding or disbelief by professionals" (Rawlings and Reuber, 2016: 106). As one patient put it, "As long as others understand me, and don't think I stage or simulate seizures, it is all right" (Karterud et al., 2015: 110). The provocative test is likely to affirm such concerns in patients. Not only do they feel distrusted by their caregivers, but those caregivers have devised tests in order to catch them in their perceived dishonesty, and in doing so, document a justification for their distrust. As such, patient distrust is well-founded, and it is unsurprising that feedback loops are often created between the distrust of providers towards patients and distrust of patients towards providers (Buchman et al., 2016). This should give one pause in thinking about the ways of relating that may be engendered through the use of terms like 'treatment resistant', 'non-compliant', or 'difficult patients', which often circulate in medical settings, particularly those dealing with the 'psychosomatic' terrain (Chamberlin, 1998).

Paternalistic magic?

Western medicine is known for its long tradition of paternalism, particularly in areas of medicine concerned with the mind, as in each of these cases (Code, 2018; Code, 2006; Munthe et al., 2012; Loignon and Boudreault-Fournier, 2012; Hansson and Fröding, 2020). The authority and superiority of the doctor is cultivated in a multitude of ways and places, within healthcare organizations, among the profession itself, but also societally. The knowledge of the doctor is seen as exclusive, an authority with limited access. Western history is fraught with instances where the medical profession has been used to deprive others of their knowledge, experiential or other (Merchant, 1981;

Code, 2006). Such instances are especially common in cases of those who are defined by their unreason, by virtue of being considered mad (Foucault, 2003).

Such paternalism can also be seen in the selection – *storying* – of the patients chosen for beneficent deception in medicine. Who better than children, aging adults with cognitive impairments, or women who might be ‘faking it’, and particularly those with conditions seen as hopeless? Because we’re used to seeing each of these groups treated paternalistically, they are natural and fitting audience members when it comes to deceptive practices in medicine. Selecting such participants as candidates for beneficent deception is a form of misdirection; it invites us to focus on their lack of autonomy and the likelihood of benefit, as opposed to the trickery involved.

Which characters are given voice when these stories are told?

Another form of misdirection can be found in the way ‘characters’, in each of these stories, are given, or not given, voice. In each story of medical innovation, characters must be developed and described. As we have seen, the characters being deceived and those doing the deceiving fit within preconceived notions of control and agency. But who takes center stage in the telling of the story, of the regaling of the trick, depends on how successful it was. A magician is celebrated for a remarkable trick, just as researchers, architects, and doctors are congratulated for their successes. In cases when these experts fail to execute their vision, however, other lines of visibility, responsibility, and blame are drawn.

Placebo Machine

In Olson et al.’s (2021) reporting of the placebo machine, the voice of only one participant from the experiment appears within the authors’ manuscript. This participant, 12 year old Maria, had been compulsively picking her skin, while awake and asleep, for two years. Her mother has been required to bandage her arms and face each morning and she frequently developed skin infections. However, after her experience with the placebo machine (including an additional session

provided by the researchers), Maria experienced a miraculous recovery. While all other participants are spoken for by their parents or by the researchers within the article, Marie is quoted directly:

At first I was confused, because I was just going into the machine and I was like, “What is this doing?”...

And then after another two sessions, I started to notice you feel more relaxed, calm, confident. And I noticed I wasn’t picking as often. I didn’t have the urge to pick.

When you [exit the machine], you learn how to lie down and go into that same state that you were in inside the machine, and after a few sessions, you don’t even need the machine any more. So if I have another problem, I can just do it myself now. (Olson et al., 2021: 5-6)

An ideal audience member, Maria offers compelling evidence for the magic of the placebo machine: not only does her urge to pick disappear, but she is able to access the healing qualities of the experiment on her own, without the need for the elaborate show contained within the experiment. As suggested by the researchers, *her brain is healing itself*.

Those who did not fare as well as Maria are given much less voice within the scientific story of the placebo machine, however. In particular, one child who participated in the experiment “demonstrated no noticeable improvement” (Olson et al., 2021: 7). While very little is said about the participant, the authors point out that the 6 year old “was oppositional with his mother and the experimenters”, “showed little interest in the procedure”, and “expressed scepticism about the machine” (Olson et al., 2021: 7). It seems that, in this case, the audience was uncooperative and unwilling to play along with the magic trick. In analysing the lack of effect of the placebo machine on this participant, the researchers point to the ‘oppositional’ nature of the child as well as his ‘scepticism’, suggesting that the failure of the experiment can be located ‘all in his head’. Nothing is said about other factors that may have contributed to the child’s experience, directing blame and responsibility solely towards the 6 year old child who lacked enthusiasm for the placebo machine. This type of narrative is common in placebo research, in which one’s attitude or mindset is often thought

to be an essential ingredient of the causal story (Friesen, 2019). These dual explanations, in which a participant is blamed for an unsuccessful experience, and the magic of the experiment credited as a successful experience, misdirect audiences towards one form of causation when results are positive and another when results are negative.

Dementia Villages

In discussions of dementia villages, the voices of the most crucial audience members, those living with dementia, seem entirely absent. Despite reading widely on the topic, we could find no retelling which included the voices of residents or lived experiences of the villages. Instead, the comfort of family members dominate in discussions of dementia villages. An article describing a Canadian dementia village simply called *The Village* (in Langley, near Vancouver) includes pictures of a mother and daughter, the former being a resident of *The Village*. Interviews, however, only include the daughter's experiences. Residents are mentioned throughout the article in relation to their ability to "roam free" and "wander", inviting comparisons with animals or children (Griffin, 2019). Moral discussions of dementia villages also center around family members, especially the difficult choices they must make about where to "put" their loved ones⁴. This focus naturalizes the idea that those with dementia or cognitive decline cannot be involved in decision-making processes or have autonomous goals, needs, values, or desires. Communication with them is seen as impossible, rather than difficult or different. People with dementia are construed as entirely and irremediably lost in their heads, their independent realities, inaccessible to others who are required to make decisions for them⁵.

Provocative Testing

Here too, the voices of those most likely to be administered provocative testing are mysteriously absent. A recent systematic synthesis of 21 qualitative studies describing the experiences of patients who have been diagnosed with PNES, the topic of provocative testing does not arise once (Rawlings and Reuber, 2016). Despite being a common topic in medical literature related this condition, the views of patients on these decep-

tive tests seem not to be sought within qualitative research. The absence of patient voices serves to create particular kinds of characters in the stories told about provocative testing, those that 'raise suspicion' from medical practitioners in terms of their capacity and likelihood to 'tell the truth'. In contrast, despite lying to patients, clinicians are described as beneficent and worried about engaging in such deception; as one paper puts it, "Courage is needed to communicate the diagnosis, which may be emotionally taxing for all parties involved" (Takasaki et al., 2016: 7). Patients, in contrast, are portrayed as suspect, thus reinforcing notions of responsibility and blame that linger in the background of stories of provocative testing, but also justifying that doctors must make those difficult decisions of choosing deceptive means, to help the patient – *in spite of themselves*. Furthermore, the test doles out responsibility for one's suffering with immediacy and certainty. The provocative test is said to determine *once and for all* the cause of the patient's seizures – particularly whether the source of their suffering is 'all in their head'.

Partial Stories

These stories are revealed here as *partial* stories (Haraway, 1988)⁶. All tellings are partial (perspectival and incomplete), but the vast majority are told from the point of view of omniscience in Western culture, as Haraway (1988) points out: the way the story is framed, as precisely *not* a story but the 'sole presentation' of facts⁷. As a result, no other storyline is allowed. The medical stories presented above stem from the perspectives of magicians, of experts; readers are thus (mis)directed towards some characters in these stories and away from others. With the exception of Maria and her miraculous recovery, essential players in these stories vanish within their tellings. Yet despite their invisibility, 'audiences' – those on the receiving end – play a crucial role in successful magic tricks. A magician cannot perform to an empty room, just as researchers require participants, architects require dwellers, and clinicians require patients, on which to exercise their expertise as well as explore innovative techniques. Every telling makes choices, highlighting some parts of a story and leaving some out, conveying what is deemed

valuable or not, what *matters* or not. In these stories, some characters are made up as good/responsive (Maria), as bad/non-compliant (the skeptical child), as invisible/non-communicative (residents of dementia villages), or as untrustworthy/malingering (patients presenting with uncommon seizures). As such, new kinds of patients are made up, and with them, new spaces of possibilities, new moral concerns, and new medical practices arise (Hacking, 1986).

How is deception justified within these stories?

Across each of these stories, deception looms large, and those writing the stories are well aware of its centrality. In discussions of the placebo machine, dementia villages, and provocative testing, ethical musings on deception take up considerable space. Misdirection takes place here too, following a familiar bioethical arc, in which beneficence and autonomy are in conflict, and one must be chosen to win out. In each of these stories, the importance of the benefits gained from deception are emphasized and the losses associated with being lied to are downplayed, directing readers away from the risks of dishonesty in medicine and towards the fruits that can be gained from such dishonesty.

Placebo Machine

Despite placebos being known as “the lie that heals” (Brody, 1982), the researchers behind the placebo machine offer a nuanced discussion of the way deception shows up in the project. On the one hand, they note “in our study, there was little lying”; on the other, they admit “the procedure used copious implicit deception” (Olson et al., 2021: 7). As a result, deception in the placebo machine experiment is complicated to trace. The researchers note that on the initial phone call: “We fully briefed parents on the procedure, explaining that it was non-invasive and based on the placebo effect as well as positive suggestion” (Olson et al., 2021: 3). Later, before entering the scanner, participants and their families were told that “everything that we say and do, everything you see around us, this equipment, these lab coats, as well as the machine” is part of the suggestion procedure

(Olson et al., 2021: 3). Despite this, a number of aspects of the study mislead participants and their families into thinking that the machine is *anything but* inactive: when entering the scanner room, participants and family members were asked to remove any metal objects from their pockets, an action that might quickly replace an understanding of the machine as inactive as one that is active (Olson et al., 2021). In addition, celebrity endorsements, lab coats, high-tech equipment, cognitive reframing, positive suggestions, and the camera crew, all suggested that the machine was something special (Olson et al., 2021).

Olson and colleagues, well aware of the dynamics of magic shows, note that “telling audiences that a performer is a magician does not stop them from believing the magician has supernatural powers” (Olson et al., 2021: 7). Similarly, with the placebo machine, children and parents alike continued to act as if the scanner was active and powerful, even after being assured that any healing was self-healing. Olson and colleagues suggest, in response to this complex reality, that deception should not be thought of simply as lying or failing to tell the truth, because implicit factors can deceive just as much as explicit statements. Instead, they offer, deception might be best conceptualized as “based on its outcome (i.e., participants holding false beliefs) rather than its process (i.e., the type of deception used)” (Olson et al., 2021: 7). This suggestion aligns with an emerging research programme focused on open-label placebos, placebos given to research participants who are well aware that the pills they are taking are ‘mere placebos’, but who have been encouraged to think about the power of placebo effects and take the pills in a regular, ritualized way (Kaptchuk, 2018). Some of the early experiments involving open-label placebos have been remarkably successful in generating symptom relief in research participants who suffer from migraines, chronic low back pain, and irritable bowel syndrome, as well as children with diagnoses of ADHD (Kaptchuk et al., 2010; Kam-Hansen et al., 2014; Carvalho et al., 2016; Carvalho et al., 2020; Sandler and Bodfish, 2008). This research indicates that the narrative of placebos as merely lies that heal may be too simple. Instead, it opens up space for a more complex, and perhaps more magical,

understanding of placebo effects, one that doesn't require (explicit) deception for success.

Despite their honesty about deception, the manuscript by Olson et al. contains an implicit argument in favour of using deception in medicine for the sake of beneficence⁸. By highlighting the stories of success and downplaying the narratives of 'failure' with the placebo machine, the authors shape a story of promise, of healing potential, that outweighs any concerns about autonomy that may be bubbling up in the background.

Dementia Villages

Misdirection in discussions of dementia villages acts at the level of directing attention and awareness away from other questions and critiques of geriatric care facilities and the 'management' of aging adults with cognitive issues. This is done notably by creating a false dichotomy and therefore a false choice between two, oppositional, options. This dichotomy offers, on the one hand, the cold, depersonalized, fluorescent geriatric care facility that is associated with possible (re)traumatization and exacerbation of ill-health, aggressive behavior, confusion, disorientation, and depression, and, on the other hand, dementia villages, described as warm, familial, friendly, comforting, playful, innocent, validating, and fuelled by good intentions. As Adams and Chivers have pointed out, dementia villages, construed as caring villages, offer "a direct counterpoint, in every conceivable way, to the uncaring institution" (Adams and Chivers, 2021).

While dementia villages inscribe themselves in a *social turn* in care, these new models are not without important criticisms (Dolan, 2010; Cribb, 2000). Most criticisms emphasize the problematic 'normalization' of lying and deception, for some people, and how such facilities are inherently infantilizing and patronizing for the elderly, therefore negative (Steele et al., 2020b; Steele et al., 2020a). The social construction of the older person with cognitive decline, as no longer reachable, *lost* in the person, serves as justification for playfulness from family members and carers and a sense of 'deresponsibilization' with regards to truly getting to know the new person. Furthermore, despite dementia villages being described as utopian settings where residents

wander happily in innocent reminiscences, these settings raise questions in terms of the human rights infringement of most dementia care facilities that promote the isolation and perpetuate the containment of people with dementia. Adams and Chivers note that, "the dementia village is a walled, gated community, not unlike a prison in its site plan" (Adams and Chivers, 2021). Residents in dementia villages remain removed from and even prevented from contact with the rest of society; they cannot access other communities. This increases the likelihood of abuse and neglect behind closed doors. How dementia villages replicate these aspects of standard geriatric facilities is largely absent from the mainstream narratives about these new and promising designs. The question regarding the residents' capacity to be part of the larger community, of society, remains brushed off.

The central role of deception in dementia villages is frequently justified through the invocation of beneficence. A news article describing De Hogeweyk notes that the "residents ... require fewer medications, eat better, live longer, and appear more joyful than those in standard elderly-care facilities" (Tinker, 2013)⁹. This aligns with justifications that practitioners offer when asked about the role of lying in dementia care. As one therapist put it, "that's why we have to tell a lot of lies. Because it's for their benefit" (Tuckett, 2012: 13). In line with this, draft guidelines developed for the practice of lying in dementia care list as the first guideline "Lies should only be told if they are in the best interest of the resident, e.g. to ease distress" (James et al., 2006: 800)¹⁰. But who is most likely to benefit from a dementia village, and therefore sought and selected to become residents? These villages harken back to a time that may be remembered much more fondly by some than others. In De Hogeweyk, residents can choose rooms decorated according to seven archetypes, said to reflect the Dutch population: Homey ("a simple life, focus on housekeeping and family"); Christian ("religion is an important part of life, may affect lifestyle choices"); Craftsman ("traditional, hardworking, early to rise/early to bed"); Arts and culture ("international travelers, colorful interior design, more adventurous in food choices"); Aristocracy ("formal, classic design,

accustomed to having servants"); Indonesian/Colonial ("interested in nature, spirituality, Indonesian food"); and Urban ("outgoing, informal") (Glass, 2014: 77)

These themes/archetypes raise questions regarding the cultural biases and social norms that can be reproduced and reinforced, including those fostering social discrimination. Favouring the 'familial past' is presented as comforting, non-confrontational, validating, but it raises the question of who are the ideal residents and how racism, sexism, homophobia, etc., can be naturalized. "You're allowed to live in the mental and physical space that makes you the most comfortable", says one author describing dementia villages (Rogers, 2018). For whom is this replicated time most comfortable with for, is the question we are left with¹¹.

Provocative Testing

Discussions of the ethics of provocative testing, given the trickery involved and the importance of trust and autonomy in medicine, are common. As above, the importance of weighing risks and benefits dominates these discussions. As Takasaki and colleagues ask, does the "harm of subterfuge outweigh the good that comes from an expedited diagnosis?" (Takasaki et al., 2016: 7). Many discussions point to the costs of not using deceptive testing for diagnosis. Diagnosing PNES through other means, we are told, is lengthy, resource-intensive, and demanding on both patients and practitioners. Seizures often occur infrequently, and are therefore difficult to document, record, and examine. Equipment for EEG testing is not usually at hand and easy to hook up in time. By contrast, the deceptive saline test is viewed as rapid, relatively safe, and relatively effective. Because the treatment is 'merely a placebo', the physical risks are thought to be minimal; and after the test is finished, there seems to be no doubt that a seizure or other negative effects will cease automatically once the injection is stopped.

Most importantly, having a definitive diagnosis, and sooner rather than later, is viewed as primordial. Selim Benbadis argues that it is *unequivocally more unethical* to leave a patient without a diagnosis or with a wrong one for these could have dire medical consequences (e.g. fatality)

(Benbadis, 2009). Deception is unequivocally justifiable because 'life', the ultimate principle, is threatened. Yet how this argument is made can itself be likened to misdirection. The reader is led to weigh the *wrongness* of receiving a wrong diagnosis, but directed away from the harms of deceptive diagnoses or alternative options. Such a discussion misdirects the reader away from the fact that provocative testing is neither necessary nor the sole option (Bernat, 2010). Critics of provocative testing point to the harms that can be caused to the patient-physician relationship through the deception involved, especially given common histories of abuse and challenges related to establishing trust in patients diagnosed with PNES. Burack and colleagues also point to the "anger and humiliation" often felt by patients with PNES after discovering that they have been deceived by their provider, and how in some cases, these patients do not return for further care (Burack et al., 1997). Benbadis, however, dismisses ethical concerns about provocative testing as outweighed by the importance of beneficence and non-maleficence, misdirecting the reader and perpetuating the story that there are instances where this test is the only option – *without it, a wrongful and harmful diagnosis is likely to follow* (Benbadis, 2009).

Stories that matter

Above, we've shed light on how each of these cases are tellings, stories that come with particular frames and not others, that enact selective views, orient and misdirect audience members – controlling the 'story'. Elements of the story, including who the (direct or distant) audience is, what the trick consists of, who the magician(s) might be, and what the outcomes will be, are carefully thought out, crafted, and controlled by those in positions of authority and power, at the costs of the voices of audience members – children, aging adults with cognitive issues, females with a history of abuse and suspected of deception. Yet stories matter, in more than one way. Stories have material effects in addition to discursive ones. These material effects include unforeseen effects such as, in the case of the children experiencing the placebo machine, taking full responsibility for the absence of positive outcomes and their 'defective brain' which is unable to heal itself; in the case

of adults with dementia, failing to engage (with) them as whole *and new* people, who have desires, goals, fears, etc.; in the case of women suspected of faking it, jeopardizing their ability to form therapeutic and trusting bonds with others, including health professionals.

In this section, working with the contributions of F/STS and Feminist New Materialism (FNM), we explore the underlying and unavowed assumptions in the medical narratives that sustain each of our medical cases, paying particular attention to the entanglement of the material and the discursive in how these stories are told, framed, and enacted.

What of reality?

Here, we consider: in these stories of beneficent deception, what are the unquestioned assumptions about the real, about reality? And how are these assumptions produced and reproduced, perhaps enforced, through both the prospective (hopes) and retrospective (attributed outcomes and causal links) tellings of these stories? We ask: is this *really* how the world is? And if this isn't *really* the way the world is -- who, if anyone, takes responsibility for these assumptions about (and their effects on) the real and causation?

In magic and Western medicine, it is assumed that there is one reality, which is fixed, immutable, stable. Magic is a trick, an illusion, which manipulates known physical features of the world, of a world that is deemed 'known'. Medicine does the same, working its miracles through manipulations of the patterns, structures, and components of the body. Underlying these tricks is the unfaltering assumption that there is *a* real, a real that is *really real* – that is, fixed and known/knowable using the scientific method. In medicine, one seeks to know this reality completely, and harness it for the benefit of patients. In magic, playfulness and enchantment offer a temporary 'escape' from a 'disenchanted' (a.k.a. scientific/known) world. One 'pretends' its unfaltering physical laws can be bent, for the fun of it, but all the while continuing to hold that tricks exist only 'all in the heads' of audience members, brought about through the magician's clever manipulations. All the while, the real remains unchanged.

Yet is it 'truly' the case? Perhaps not. F/STS and FNM highlight how the Western traditions of science and philosophy have long operated under an ontological assumption, that the world is fixed and that things (e.g. matter), conceived as endowed with essences that transcend time and space, can be known (i.e. 'discovered') using an appropriate method, i.e. the scientific method (Alaimo and Hekman, 2008; Barad, 2007). These scholars push against these assumptions; working with novel developments in the 'hard' sciences (e.g. chemistry, physics, biology, geology), they show that reality is not endowed with a fixed ontology, but rather is ontologically open, indeterminate.

In her work, Karen Barad uses the work of quantum physicist Niels Bohr to show how the physical world is not, as we often think, endowed with fixed properties, but is, at the 'core', without any, and rather always *in-the-making*, *indeterminate*, yet *performative*, and becoming, but only in context and relationally (that is, with other things, *bound* to these other 'emerging things', which include both material and discursive things) (Barad, 2007; Barad, 1996). Bohr argues that *measurement* in science is what contributes to the *configuration* of material matter. Measurement influences matter-as-indeterminate to solidify/stabilize itself, thus becoming available to scientific observations, that is, *representationable*. This is evident in the case of the famous particle-wave experiment, where light, depending of the apparatus used to observe it, will either display *particle* or *wave-like* behavior, two facets that are traditionally conceived as irremediable and incompatible (for more, see Barad, 2007).

This experiment is famous because it reveals the non-static 'state' of our reality, its inner indeterminacy. Things may acquire something akin to an essence, an identity, but they do so only temporarily, in context, as well as relationally; with other things (other material things or discursive matters); *intra-actively*, too, rather than *inter-actively*, meaning that there are no things that pre-exist *relata*. Things are co-constituted: they become together-apart, always linked, and such links are essential to any investigation that aims to acquire knowledge. So it is, too, in stories of beneficent deception in medicine. Placebo effects

cannot occur outside of relationships. There is no inherent power in a sugar pill; rather its meaning is derived from an assemblage of actors, factors, and constructed meanings. In provocative testing, a diagnostic trick is said to reveal the etiology of a seizure, but each seizure produced in such a setting was created not merely 'in the head' of the patient, but also a result of a coordinated performance involving medical tools, suggestions, and moral framings. In dementia villages, no absolute reality exists, but temporary ones are enacted through relationships between residents, carers, and family members, all partaking in a process of creation within a suggestive environment. As Shannon Mattern recently suggested in a discussion of dementia, "Perhaps we need to move away from this sort of binary logic of recognition and reality, which tends to focus on fixed identities and reciprocal relations. Perhaps we might instead consider spaces of containment, like the closet — or even the dementia village — as sites of creation, transformation, and mediation; as incubators of epiphanies, dreams, fears, memories, new relations, new worlds" (Mattern, 2021).

What of causation?

Medical knowledge, much like the Western traditions of scientific knowledge, is known to approach events in the mechanic conception of causation. In this model, the reductionist approach is used to simplify the world, to attribute power to discrete things, and determine causes and effects, simply. Like F/STS, placebo research disrupts medicine's longstanding causal lines between causes and cures. A pill is no longer merely a pill, but a pill embedded with meaning and history, which cannot be left out of the causal picture (Berkhout and Jaarsma, 2018; Moerman, 2002). Aspects of the clinical encounter that are ordinarily thought of as 'the art of medicine' begin to make their way in the causal story of what constitutes healing. In this way, it becomes clear that in realms where the placebo operates, a cure is never just a cure, but is imbued with its power in part through placebo pathways that have been activated through various means. While credit for the clever experiment belongs with the research team, the children are repeatedly told that they are responsible for their own healing, as their

brains learn to heal themselves throughout the experiment. While such a narrative may be helpful to these children, it cannot be said that the brain is the sole agent of healing in this story. Things are more complex and always relational, as F/STS scholars and those versed in the *new/immanent ontologies* point out¹². This is reminiscent of Elizabeth Wilson's analysis of the endless quest to disentangle placebo responders and anti-depressant responders. As Wilson points out, there is no clean break between these, because "the response to the medication and the response to placebo are parasitic on each other" (Wilson, 2015: 132).

In the placebo machine, the notion of a singular cure no longer makes sense. Instead, we must look to an assemblage of contributors – the patient, the treatment, the environment, the healer – among other things and dynamics and the way each of these elements are related, in order to understand what has taken place. The placebo machine distributes causality in various directions – towards celebrity endorsements, social proof, institutional credibility, a large team and camera crew, lab coats, high-tech equipment, cognitive reframing, positive suggestions, a peer mentor, and space music. As such, the singular cause of the cure, a central assumption in evidence-based medicine, on which the randomized-control trial is founded, is lost. But why is it *this conception* of causality that dominates our thinking? Is this really 'how all things work', that is, that things can be dissociated, separately neatly, kept at bay, and simplified, while a single cause-to-effect is established?

In her work of rethinking realism and ontology with the concept of agential matter, Barad (2007) shows that once you have shown that things do not have essences or identities pre-existing their relata, it becomes harder to attribute clear causal lines between things. Indeed, where does one thing stop and the next one begin?

Causality is most often figured as a relation between distinct entities. ... But according to agential realism, separately determinate entities do not pre-exist their intra-action. So how are we to think about causality in this account? ... On an agential realist account, causal relations cannot be thought of as specific relations between isolated objects; rather [they] necessarily entail a

specification of the material apparatus that enacts an agential cut between determinately bounded and propertied entities within a phenomenon (Barad, 2007: 175-176)

In Barad's view of *intra-action*, 'causality' refers to the process of separating that which was not separated in the first place, but there is nothing that comes first; rather, we only have a 'becoming apart-together'. This is also why Barad moves away from concepts such as 'nature' versus 'culture' or 'subjects' and 'objects' in knowledge inquiries. She proposes instead those of *agencies of observation* and *objects of observation*, whereby 'observation' clarifies that the moment of stability that enables knowledge claims is a made-situation of *interiority* where stability has been achieved and 'identities' can be respectively attributed. But their 'identities' are intricately and irrevocably linked; they cannot be dealt with or known independently from one another. What they 'are' is true only when one considers their relations (Barad, 2007).

Assumptions of causation are also deeply embedded in the practice of provocative testing. These tests rest on a dichotomous premise of one, legitimate, bodily cause (epilepsy) that can underlie seizures, versus another, illegitimate psychological cause that can also lead to seizures. Of course, this set up presumes the highly unlikely dualism between mind and body that Western medicine rests upon. What's more, one cause does not rule out another cause. What is rarely mentioned in ethical discussions of provocative testing is the uncertain efficacy of the test. Because patients who have PNES can also have epilepsy, the deceptive test could prove nothing; it may indicate that the patient has PNES but can not in fact rule out epilepsy.

Furthermore, it is worth asking what causation is really contributing in provocative testing. If the patient fails the doctor's trick and is determined to have non-epileptic seizures, one hypothetical ('psychogenic') cause replaces another ('epileptic'), but provides no additional explanatory information. This is reminiscent of Isabelle Stengers' discussion of the commission appointed to investigate Anton Mesmer in the 18th century and his claim that he could heal patients through his mysterious magnetic fluid. Using the trickery of blinding now commonly used in randomized

control trials, the commission concluded that Mesmer was a charlatan, and that what explained the relief felt by his patients wasn't the fluid, but the imagination. But, as Stengers points out, the imagination is just as mysterious as Mesmer's magnetic fluid. Just as with psychogenic seizures replacing epileptic ones, reframing causation can be "just a way of disqualifying the phenomenon rather than understanding it" (Stengers, 2013: 22).

In science and medicine, causal stories are often sanitized to exclude the places in which ignorance or accident co-exist, despite these being central parts of their construction. Consider Barad's discussion of an unseen causal contributor in the Stern-Gerlach experiment from quantum physics 'First, an explanation of the experiment':

In the original experiment, silver atoms were sent through a spatially varying magnetic field, which deflected them before they struck a detector screen, such as a glass slide. Particles with non-zero magnetic moment are deflected, due to the magnetic field gradient, from a straight path. The screen reveals discrete points of accumulation, rather than a continuous distribution, owing to their quantized spin. Historically, this experiment was decisive in convincing physicists of the reality of angular-momentum quantization in all atomic-scale systems. (Franklin and Perovic, 1998; Gerlach and Stern, 1922; Friedrich and Herschbach, 2003 cited in Wikipedia, 2021)

It took many tries however to successfully achieve this observation as Barad reports (2007). Stern, a leading scientist in the domain, was key to this. Before a particular involvement on his part in the experiment, leading scientists in the world were abandoning this experiment and hypothesis all together. In Barad's words:

Stern held the plates in his hands and studied them at a distance close enough so that the plates could absorb the fumes of Stern's sulfuric breath, turning the faint, nearly invisible, silver traces into jet black silver sulfide traces (Barad, 2007: 165)

Stern, you see, used to smoke a specific brand of cheap cigars. The composition of this type of cigar is decisive, allowing him and his fellow scientists to make the observation reported above – and the contribution we now know to science and quantum physics:

The reproducibility of the experiment depends on the cigar's presence. Not any old cigar will do: the high sulfur content of a cheap cigar is crucial. Class, nationalism, gender, and the politics of nationalism, among other variables, are all part of this apparatus (which is not to say that all relevant factors figure in the same way or with the same weight) (Barad, 2007: 165)

Here Barad explains why Stern smoked this cigar, and not another kind, and how this decision depends intimately on his embodiment, gender, nationality and nationalism, economic class. All these facets came to play a decisive causal role in the production of *this* knowledge, and are vital to its reproducibility. How, then, can each 'magician' in the above cases hold complete knowledge of the causal effects of their experiences?

All stories are made... but not 'made up'

These assumptions, about reality, about causation, including their fixed, inert, and 'discoverable' natures, are thus questionable. The main problem – or rather the main consequence – regarding these assumptions is that it fosters the creation and maintenance of *blind-spots* and *gaps in accountability* for the notably active role that those involved in scientific and medical practices play. This lack of accountability for those in positions of authority in each case is further witnessed when one examines how little attention they pay to the active role they play in *making* the stories, the narratives. This goes for the medical scientists as well as practitioners that rely on deception. That is, in creating the 'reality' that they so-direly assumed to be 'true', that is, *fixed*, immutable. But all stories are created, made. To create a story, one has to make choices, to leave some things out, to insist on others. It is always a framing. By adopting one story of 'truth', these practices perpetuate the invisibility of other mechanisms that could be at stake, that could be taking place. Some stories are made visible, while others fade into the background.

In dementia villages, a particularly enlightening example of how 'stories are made', a past is imagined, which is based on a particular time and perspective and further enacted (i.e. reproduced concretely in the context of the care facilities). Those designing such settings must decide, in

crafting this renewed past: For whom is this past (re)made? The residents, or for carers and family members? Whose voices are involved, sought? What is removed from the past/story, and how? How is it curated, purified¹³, for the residents (e.g. cleansed of sexism and racism)? How much do the makers/creators: deal with the reshaping of the past?; convince themselves that they are not makers/creators, but simplifying (and successfully) copying a past that would exist as fixed?; reckon with the unforeseeable consequences and construction of the past?¹⁴ Such decisions are made throughout the construction of any story, any magical enactment within medicine. Our tendency to erase authorship, the role of those telling the stories, is a worrisome one.

Coda: Embracing magic in medicine?

Medicine is magic/al. Yet what if this 'fact' was acknowledged and embraced by practitioners and researchers alike? There are so many things we do not know about medicine: how knowledge is constructed, how treatments work, which treatments works, and so forth. This recognition, however, continues to be ignored, denied, brushed off. Why?

Unsurprisingly, in a scientific paradigm that remains highly positivist, realist, and reductionist, that adopts representationalism as its main approach to knowing and that aims to put into clear, mutually exclusively, discrete boxes of 'thingified things' (Barad, 2007; Barad, 1996), an acknowledgement of the absence and impossibility of *complete* knowledge, and of clear and direct cause-to-effect relations, appears impossible. In biomedicine, where objective expertise is held as a necessary condition for authority and effectiveness, how could ambiguity and indeterminacy be embraced?

While magic tricks take place in a world in which reality is known and manipulated, another form of magic, that which is unexplainable and mystifying, leads us to experience wonder in light of our own epistemic limitations. Is there space for such wonder in medicine? Of course, purposefully and intentionally *infusing* magic into medical (and bioethical) practices should be done with careful care, and respect, as well as trust. Feminist New Materialism speaks of knowledge endeavours in

light of their new dynamic ontology as needing to embrace and practise an *ethic of response-ability*, which is a caring, future-oriented, responsible and responsive *ethico-onto-epistemological* practice, one that recognizes *and embraces* the inseparability of ethical, ontological, and epistemological considerations and the inherent dynamism and indeterminacy of our reality:

[M]any feminist engagements with the diagnosis of the Anthropocene focus on a re-conceptualization of the notion of responsibility as *ability to respond* or *response-ability*: Haraway works with this notion in her discussion of human-dog-relationships, examining the development of an ethos of curiosity and a practice of responding with otherness (Haraway 2008, 19–27; Haraway 2003); Karen Barad (2007, 391–396) pleads for an ‘ethics of entanglement’ (Barad 2012, 47) that acknowledges the inherent ethical dimension of all worlding;... by emphasizing constitutive impurity. Alexis Shotwell (2016, 48–54) shows that a practice of responding in these troubled times cannot refer to an idea of purity, but has to push forward a decolonizing memory practice. All of these approaches share the idea that there is a need to go beyond individualizing notions of responsibility in addressing the multiple, never fully graspable interdependencies of the present condition. The notion of response is therefore key for a post-anthropocentric feminist ethics. (Hoppe, 2020: 126, citations in original)

In ‘troubled times’ full of complexity and entanglements (Haraway, 2016), we need to embrace magic in a way that brings out our *capacity* to respond, and that of those working in medical research and practice; mere beneficent deception will not do. Ian Hacking warns that knowledge practices tend to dismiss mysterious and marvellous phenomena. He notes that “one way to silence a topic of research is to treat it as a curiosity or turn it into a marvel. Science abhors a marvel, not because marvels are vacuous, empty of meaning, but because they are too full of meaning, of hints, of feeling” (Hacking, 1998). But what would it look like to turn towards marvels, towards that which is magical in medicine?

Isn’t there something mysterious, perhaps magical, in the way our brains produce seizures as a result of our trauma? Why dismiss this remark-

able event through a deceptive test and a referral to a psychiatrist? Something fascinating and challenging is often taking place in the stories that resist, that push against our boundaries and boxes. In medicine, the boundary between the mind and the body is one of the most firmly established. Nonepileptic, pseudo seizures, or *spells*, collapse this line, refusing to exist on one side or the other. While patients who experience such seizures are tossed back and forth between neurology and psychiatry, never quite belonging, they are also challenging a fundamental assumption, of *reality*, built into medical practice. By transforming their trauma, their pain, into a physical experience, these patients are performing a remarkable magic trick, one that we cannot understand. But rather than eliciting our wonder, our compassion, and our curiosity, we suspect them, we deceive them, and we dismiss them from the places where they seek help.

What of dementia villages? These villages don’t only offer a form of validation for those living with dementia, but a fictional place for all of us. Can they offer a bridge between the often disparate experiences, and mental worlds, of those living with and without dementia? There is a magic in how we are shaped, directly and constantly, by our environments, and dementia villages may provide an avenue by which we can come to appreciate this constant influence, and better understand that there is no single reality, some exist in and others don’t. And now may be a better time than ever to reach for this understanding. As Mattern points out, “The epistemological crises of recent years — conspiracy theories, political factionalism — demonstrate just how tenuous is the concept of a “shared reality” against which a demented ontology might be measured” (Mattern, 2021).

The placebo machine is also a good example of medical practice that embraces the principles of magic. In leaning in to a fantastical magic show set up by researchers, these children have found ways to heal, not merely by healing themselves, but through a complex causal picture involving their brains and beliefs, the relationships they are embedded in, their histories, and an extraordinary environment. In this experiment, the limited knowledge of biomedicine and traditional Western knowledge practices is recog-

nized – and accepted; the experiment proposes a *situation*, inhabited with various practices and objects, discourses, dreams, values, from which a magical response can happen, that of healing. Where and how the healing happens is not clear. But something *does happen*, and novel forms of healing are explored, even celebrated.

William James was interested in the question of when it is reasonable to believe something in the face of uncertainty. He suggested that there are some cases in which “faith creates its own verification”, and in these instances, we might find “the

will to believe”, despite uncertainty (James, 1897: 97). In such cases, he argued, belief is the only way to access particular outcomes, even though belief may not be justified on epistemic grounds. Where in medicine might we invite belief in the face of uncertainty, unknowing, or ignorance? The placebo machine is one such story. In this experience, belief, despite uncertainty, may be part of the causal storm that contributes to relief in these children. This, it seems, is a magic worth embracing. But we must be careful not to limit our attention only to those children who play along.

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Notes

- 1 The 'ontological turn' refers to a paradigmatic shift in the sciences and humanities, where the immutability, endurance and fixity of the *ontic*, the physical reality, is questioned, and *ontology*, the inquiry into the matter of things, no longer viewed as a practice that leaves unaffected what it studies. For more on this, see (Pickering, 2017).
- 2 Reliance on 'magic terminology' has a long tradition in Western Science. Sociologists such as Max Weber and feminist sociologists/science scholars such as Carolyn Merchant, Donna Haraway, and Sandra Harding, document how Western sciences have been framed and have framed themselves as 'demythifying' nature, 'disenchanted it', whereby 'enchantment' is depicted as a veil, a lure, a fog that prevents people from seeing how the world truly is (Weber, 1946; Harding, 1986; Haraway, 2013). Silvia Federici, Isabelle Stengers and Vinciane Despret also rely on the figuration of the witch in their writings (Federici, 2004; Stengers and Despret, 2015). What many feminists working in F/STS or Feminist New Materialisms (FNM) are, instead, doing is showing how there may be more 'magic at play' in scientific endeavors, i.e. things that we do not comprehend, that spark wonder, etc., and how 'knowledge' can emerge from allowing oneself to be available and to entice such 'affective effects'. See, for example, Jane Bennett's work on vital materialism, the thing-power, and her book on the re-enchantment of the world (Bennett, 2010; Bennett, 2006); Natasha Myers' work on scientists and how they use their bodies during the intra-action at play in scientific endeavours, as well as her new methodology mobilizing affects, plants, intra-action, and Darwin's work (Myers, 2015a; Myers, 2015b; Hustak and Myers, 2012; Myers and Dumit, 2011).
- 3 While this case involves the use of a saline injection to induce a seizure, provocative testing uses a variety of methods to do so (e.g. body part compression, verbal suggestion, placement of a tuning fork or moistened patches onto the skin, hypnosis) (Devinsky et al., 2011).
- 4 Adams and Chivers suggest that the "nostalgic design" of dementia villages acts like "an architectural analgesic", soothing and numbing "the pain of family members who may be uncomfortable deceiving their ailing relatives" (Adams and Chivers, 2021).
- 5 This isn't to deny, of course, how morally and emotionally challenging it is for family members and health professionals to support people living with dementia in processes of shared-decision making, but merely to observe the way in which ethical discussions of dementia villages focus on family members, not residents, as the key characters in the story. For studies pertaining to the exploration or use of alternative approaches and understandings of personhood, when living with cognitive decline or dementia, see (Almqvist and Andersson, 2019; Bartlett and O'Connor, 2010; Kenning et al., 2021; Leibing and Cohen, 2006; Lynn et al., 2019).
- 6 *Partial knowledges* is the concept proposed by Haraway to make clear that any knowledge emerges and is linked to a "situation", a situated, material, discursive, and necessarily *perspectival/partial*; context for the emergence and configuration of any knowledge is needed (Haraway and Goodeve, 2018).
- 7 See also Bruno Latour on 'matters of fact' as truly 'matters of concern' (Latour, 2004), a conception of science that Maria Puig de la Bellacasa pushes even further in speaking of scientific objects as 'matters of care' (de La Bellacasa, 2011).
- 8 Olson makes this argument more explicitly in other work (Olson and Raz, 2021).
- 9 Although a report by the Canadian Agency for Drugs and Technologies in Health (CADTH) found that there's currently "not enough evidence to confidently say whether dementia villages improve quality of life for residents" ((Wallington, n.d.) in discussion of (Canadian Agency for Drugs and Technologies in Health, 2019)).
- 10 Interestingly, the guidelines were developed on the basis of the views of staff only; the perspectives of those living with dementia were not taken into account.

- 11 See (Wekker, 2016) for an examination of how Dutch Imperialism continues to play a fundamental role in shaping dominant culture in the Netherlands, particularly through the notion of white innocence, which grounds the Dutch self-portrait.
- 12 For more on the concept of an *immanent ontology*, see (Cruikshank, 2004; Coole and Frost, 2010).
- 13 We use the term 'purified' in reference to how Bruno Latour and his colleagues who use the term (Latour, 2012; Latour, 1987; Lien and Law, 2011; Law and Lien, 2013; Pickering, 2009).
- 14 Haraway and other STS/FNM scholars insist that saying that knowledge is made (and through the feature of 'storying'/story-telling) does not mean that 1) things are *made up* (fictions); 2) that all stories of the real are equal (of equal value). There are, of course, some stories that are more accurate than others (Haraway and Goodeve, 2018; Haraway, 2015; Haraway, 2016; Barad, 1996; Barad, 2007).