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Thinking pain

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By Annelieke Driessen

Care worker Annika announces that she does not want to go to Mr Moran. "He always complains." "I'll go", says her colleague Robin, and turning to me he says, "I don't have the intern today so you can come along if you want to see for yourself how it goes". We head off to assemble the materials for the morning round.

"We still have the virus", Robin says, while stacking aprons and an extra box of gloves onto the cart. I had noticed the sign on the nursing home lift announcing that the dementia wards remain under quarantine. The Norovirus causes and spreads through stool and vomit and is highly contagious. Family members are advised not to visit and the volunteers are not coming to the ward to take individual residents off the ward for activities elsewhere. The care staff are in for even more work than usual: both the day and night shifts are filled with cleaning up vomit and diarrhoea. The protocol for these situations also prescribes that extra precautionary measures have to be taken to ensure that the virus does not spread: gloves are now mandatory for every care interaction in the residents' rooms, as are face masks and aprons. The fact that most residents "no longer feel the urge to vomit coming until it is 'too late'" makes the disaster complete: the many 'accidents' that happen at the dining table not only result in more and more sick residents, but also in staff members becoming sick, and thus fewer and fewer staff members who are able to take on the increased workload.

While Robin and I cloak ourselves in the light blue materials, he fills me in on his colleague's reluctance to help Mr Moran out of bed. "Mr Moran is a 'typical case of dementia'; whatever one does, it is never good enough. He always indicates pain, *always* indicates pain. In that you must take him seriously, but you must also realise that it is a repetition. He is not in pain, but he *thinks* he is in pain. It is in his head [*het zit in zijn hoofd*]." As we enter the semi-dark individual nursing home room with nothing but a sink, a bed, a closet, and some photos on the walls of Mr Moran's days as a musician, we announce our arrival with a cheerful "good morning". Mr Moran is lying on his side in bed, somewhat curled up. When Robin opens the curtains, sunlight floods the small room. "Well", he says looking at me, "we are a little behind schedule. Normally I do this on autopilot. Well... not on autopilot but, err, quicker. But now I really want to show you how it is

supposed to be done”. So he begins, and explains what he does: “The bed must be as high as your hips. If you have to bend too far it must be higher”. When Robin checks the catheter and carefully places the incontinence pad around Mr Moran’s bottom, Mr Moran says that he is in pain. There is a kink in the tube, which Robin adjusts. The urine starts running. Robin says “Ok, that could hurt indeed”. I get the tub with water for washing. Robin explains: “Washing someone on the bed means that you use the washcloth for the face first, then the chest and armpits and only then for the buttocks. Never put a used washcloth back into the clean water in the washtub”.

Mr Moran asks: “Why are you handling me so roughly?” Robin is facing him, and responds through his facial expressions – not quite warm, but certainly gentle. At the same time, he speaks to me: “He^[1] is used to a life in which he, as a Surinamese musician, is idolised^[2]. Everybody did what he said. Surinamese musicians are idolised. And what he feels now is that we take over control [*de regie overnemen*]. I don’t treat him roughly but he feels it as rough”. He asks me what I am thinking. I surely look somewhat uncomfortable standing next to the bed; the smell of urine penetrating my nostrils; otherwise pervaded by an acute sense of standing in Robin’s way; Mr Moran saying he is in pain; Robin telling me that this is not really the case. Hesitantly I say: “I think it must be difficult feeling that it is never right, regardless of what you do”. Having said this adds a sense of shame to my uneasiness about pain and my position, as my comment is so unequivocally *about* Mr Moran in his presence.

Robin helps Mr Moran to sit up, and get into his clothes. Mr Moran says that he is in pain. Robin says: “Care is necessary, but it is not always pleasant for the residents. One must just *know* that one does the right thing. Certainly from [people who live with dementia], one should not expect a thank you or even that you can always do it right. Only once I succeeded in getting a ‘thank you’ from him. But only after three quarters of an hour in which I did *exactly* what he said. That was when I was still learning, and he was my ‘fixed resident’ [*vaste bewoner*]^[3]. But of course that is impossible, especially because one has [to care for] more people. Even I have to conclude that that is not fair [to give so much time to one resident and not to others]”.

Robin lifts Mr Moran into the wheelchair that I have wheeled up to the bed. “Normally you would lift somebody out of bed with a lift if they cannot get up by themselves. I often do it this way... like the Hulk. I just lift the residents like this. Naturally, that is not entirely good for your back, but it saves time.” When positioned in the wheelchair by Robin, Mr Moran says that his clothes are too tight. Robin tugs at the clothes. The buttons of his pants are open and his shirt is wide. He shows Mr Moran that they could not be wider. Then he brushes Mr Moran’s hair. “When you are done

washing and dressing the resident, you cannot just send them to the living room to have breakfast and stay behind to clean the room.” Some would not know where to go, others could fall. “You are responsible. You must always take somebody to the living room. So you must take off your apron, mask and gloves to accompany them there.”

We take off our aprons and gloves and wheel Mr Moran to the living room. When we come back to clean the room, I stand in the doorway, the threshold between the apron-demanding space and apron-free space. Robin instructs me that it is better if I do not enter the room again, “otherwise you need to put on new gloves and a new apron; that would be too expensive”. He collects the used towels and incontinence material, and makes the bed.

Getting Mr Moran washed, up and dressed affords his participation on the ward. But in those same practices, participation may also be blocked – Mr Moran is cared for, but also dismissed as a ‘typical case of dementia’ and a ‘formerly idolised musician’. And yet participation and non-participation are not opposites. Instead, could non-participation sometimes even be the condition of possibility for others’ participation, or participation of a different kind? Perhaps Mr Moran’s way of participating in previous care encounters enabled Annika’s refusal to help him that day. Annika’s refusal to participate in Mr Moran’s care enabled, or forced, Robin’s participation. And Robin enabled me to take part.

Whose participation did I enable? Or foreclose? Did my participation as a researcher in the care interaction take away a position for Mr Moran to inhabit that would have allowed him to participate more fully?

Are possibilities to participate a zero sum game? What if the only way to let Mr Moran take part in full (if that is what the ‘thank you’ could be taken to mean) takes away time from other residents? When viruses become ‘participants’ on the ward, the opposite is true for family members and volunteers. Residents seem to get fewer opportunities to take part, as aprons and gloves take centre stage. And the threat of the virus to both staff and resident health pushes the logic of cost into the background, although it continues to play a part.

Does ‘being a typical case of dementia’ deny Mr Moran a part in the care interaction? When is pain made to play a part, and when is it not? I ask Robin what the difference is between being in pain and thinking pain. “You must be aware [that saying ‘I am in pain’] is a chorus [*een riedeltje*]. In his head, Mr Moran keeps re-experiencing and re-experiencing and re-experiencing the pain he just felt.”

There is no time to ponder these questions, and Robin’s response. Robin

rushes past me as I am still standing in the doorway. “Come on, let’s put on a new apron and gloves to help Ms. Bruinsma.”

[1] That Robin keeps talking to me about Mr Moran in the third person, in Mr Moran’s presence, highlights a tension that I am faced with and which I am part of as a researcher: in prioritising my conversation with Robin to understand better what he is doing, I am complicit in directing attention away from Mr Moran, making him the object of conversation rather than a participant.

[2] The phrasing used in Dutch was ‘op handen worden gedragen’, which literally translates as ‘to be carried on hands’.

[3] Interns are assigned a number of ‘fixed’ residents to take care of, and must report on their interactions with them.

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This post is a contribution to ‘Daily life’ in the Somatosphere series [Thinking with dementia](#).

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