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(Participant) Observation in Nursing Home Wards for People Suffering from Dementia: The Problems of Trust and Emotional Involvement

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Abstract: This contribution describes the problems and pitfalls associated with the use of (participant) observation in nursing home wards for people suffering from dementia. The research concentrated on how different nursing homes develop their care for inhabitants suffering from dementia. In order to study this, I was a known observer in four wards, each time for several months. "Getting in" to the wards did not prove to be very problematic, but "getting along" was a lot harder. There was no reason for staff to trust a snooping sociologist until I was able to convince them I was not a spy for management. It was quite clear that the information I received was influenced by the way I was perceived. Moreover, the dementia the inhabitants of the wards suffer from and their reaction to it did not leave me indifferent. This also could influence the data gathering process.

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1. Introduction

In this contribution, I would like to point out and illustrate some difficulties I was confronted with while observing in nursing home wards for people suffering from dementia. The research concentrated on how different nursing homes develop their care for demented inhabitants. In four specialized care units, I was a known observer, in each case for several months. I visited the units at different times of day and night, during week days as well as during weekends. [1]

2. "Getting in": Acquiring Permission to Observe

To get in to each nursing home, I first wrote a letter to the management, explaining what my research was about and asking if I could observe in the nursing home concerned. About a week later, I called the manager by telephone and asked for an appointment. During the meeting that followed, I answered all possible questions and made specific arrangements and agreements for the observations. Entering the nursing home was never denied or even made difficult.

> A woman brings in a can of coffee. While the manager pours the coffee, the head nurse enters. We introduce ourselves. The manager as well as the head nurse look me up and down, then the manager asks me to explain what I'm there for. I tell them about the theme of my research and the method I would like to use to find an answer to my questions. I add that I would like to test the method in this nursing home, in the ward of the head nurse present. I stress I do not want to be a burden, that I will help when and where possible, although I am not qualified to do nurses' work, and that the data will be treated confidentially. I notice the manager will agree if the head nurse agrees, which she does.[1] [2]

Sometimes, permission was only given in return for some feedback and although I did not have any difficulties to get in, it was sometimes hard to stay in because administrators asked for too much feedback at too short notice. Administrators are generally wary of a project that will essentially evaluate their personnel and institution. Therefore, they want some control over the research outcomes, fearing the results may be detrimental to the organization (MORSE, 1994, p.222). One manager explicitly wanted a report of the observations and one head nurse asked for pointers to improve the organization of the ward. In each home, I was asked to make sure they received a copy of the final research report. [3]

3. "Getting Along": Fitting in

"Getting along" in the wards proved to be a lot harder than "getting in". The toughest part was entering the setting for the first time. I felt very awkward and realised much depended on the first impression I left with the staff. Although I kept WAX's advice in mind,

> (...) the person who cannot abide feeling awkward or out of place, who feels crushed whenever he makes a mistake—embarrassing or otherwise—who is psychologically unable to endure being, and being treated like, a fool not only for a day or a week but for months on end, ought to think twice before he decides to become a participant observer. (WAX, 1971, p.370) [4]

I had trouble concealing my uneasiness. It seemed best to wait and see and let the staff and inhabitants of the wards get used to my presence, which they usually did after a period of time that differed between nursing homes. In three of the four wards, I easily found a position from where I could observe all that

1 Obviously, the data transcripts were originally in Dutch. They were translated into English for the purpose of this article.

happened without bothering anybody. The fourth ward was architecturally more complex, which obliged me to change positions often and this made my presence more visible. In each nursing home, staff thought the purpose of my being there quite strange. The fact that what I did was strange, made me a strange person and that could be quite stressing.

> The nursing assistant looks at me and then asks if I don't get bored, sitting there all the time. I answer I don't. She says she would go mad. "What is it you are watching then?" "Everything actually." "The reactions of our inhabitants?" "That too, certainly."
>
> While I wait for the elevator, one of the nurses comes up to me and asks whether my visit was interesting. She looks a bit wary when I answer that it really was. Feeling uncomfortable, I add that it may same strange, but that these visits really are interesting for my work.
>
> While the resident is still on the toilet chair, the nurse removes her sleeping gown. She now is completely naked. I feel embarrassed for my voyeurism and for the fact that I am horrified by her body that is wrinkled and deteriorated. The nurse puts a towel on her shoulders and another one in her lap. He washes her upper body, then asks if she's finished on the toilet and then he makes her stand upright. With a new washing cloth, he washes the lower part of her body. She asks him what this 'specimen', meaning me, is doing there. The nurse starts laughing and tells her I'm his boss. She doesn't answer, but pulls a face. The nurse says: "Of course she doesn't believe me." I answer she is right not to. Now I feel even more embarrassed. [5]

4. Participating or not?

I did not fully participate, since I was never trained as a nurse or nursing assistant. I rather behaved as a visiting friend or family-member, helping out when and where the occasion or the need rose, for example during meal times. Some staff member "accepted" me more easily if I participated in the work on the ward in one way or another, for instance by helping to feed some of the residents or by helping to clean up. Others on the contrary thought it strange that I would do some work and apologized extensively if I did have to do something.

> (A resident had died at a moment where there weren't many staff members present. Those available were needed to lay out the corpse and to tend to his relatives. I was left alone in the living room with the other inhabitants, who felt the tension and unease and acted upon that.) A minute or so later, a nursing assistant enters the living room. She comes up to me and says: "I don't know what we would have done if you hadn't been here." I stammer that it would have worked out anyhow. Immediately after her, a nurse comes in. She looks very tired. She also comes up to me to thank me. Staff are taking a break in the kitchen and they ask me if I would like a cup of coffee too.
>
> Mrs. A walks into the living room, in her night gown and totally confused. One of the two nursing assistants present takes her back to her room. The other one tells me someone smeared the window next to the door with buttermilk. He is looking for a rag to clean it up. I tell him I'll do it, so that he can go on with putting the residents to bed.

> He looks puzzled, but doesn't say anything. The buttermilk on the window has already dried and it takes me a while to clean it. In the meantime I overhear one nursing assistant asking the other if I am really cleaning up. While I'm on my knees cleaning, Mrs. A again leaves her room. She tells me they want to keep her here while her husband is at home waiting for her. He probably is very worried. I talk to her for a while, trying to reassure her someone is bound to have notified her husband and she wanders off again. When I return in the living room with a rag full of buttermilk, the nursing assistant thanks me several times. [6]

5. The Role of "Problem-solver"

"Knowing something" about the connections between staff stress and quality of care and about stressful conditions in the social and physical environment sometimes creates a responsibility to do something to improve daily living for people suffering from dementia and their care providers (LYMAN, 1994, p.18). In one nursing home, the two head nurses tried to use me to advocate their problems of understaffing and their concern about the incapability of some of their staff to the manager, who would not listen to them. They uttered their hope that I would be able to do something about the situation, putting a lot of trust in me and at the same time burdening me with a responsibility I did not want.

> The head nurse stops talking for a moment and then says: "I sometimes get nightmares when I think about all that I am telling you." I wave as to indicate that I really won't tell on her and she continues: "But on the other hand, I know that you're not stupid and that you see for yourself things here aren't always the way they are pictured to the outside world. Not that there are no positive sides to working here, not at all. Sometimes it's really good here, but I have only worked here for a year now and I am very disappointed. In fact, I'm quite a weak person. Not that I fall ill that easily, but I do get tired and I have to say I am in a constant condition of fatigue nowadays. [7]

6. Personal Sympathy

Obviously, I liked some staff members better than others. And some of them liked me better than others. I preferred the way some nurses or nursing assistants interact with the residents to the way others do. But I had to keep silent and not show that I was annoyed so as not to have an impact on the way the people I observed, behaved. Nevertheless, my observations are bound to be influenced by what I felt. I might have seen and heard things differently because of positive or negative feelings.

> There are only a few elderly in the ward, but they are very apathetic. One resident, Mrs. A is fixated in a chair with a table in front of it. She beckons at me and wants me to loosen her up. I tell her I can't. She forcefully tries so herself, but doesn't succeed. Six other residents are half asleep, only Mrs. B is awake, but very bored. I go and sit next to Mrs. A. Not a single staff member enters during the next fifteen minutes. Mrs. A continuously asks me to loosen her up. She addresses me with 'darling'. I feel intensely sorry for her, but I really should not move the table. I feel obliged to lie to her

that I am incapable of moving the table, but that somebody else will later on. About twenty times I have to promise her that I will look for somebody to do that in a while.

At quarter past four, a nursing aid enters. I tell her Mrs. A doesn't seem to like being fixated. She shrugs, says "Well, ..." and leaves again. I am very annoyed by now. Shortly thereafter, the nursing aid enters again and starts setting the tables for dinner, although it's only four twenty in the afternoon. Mrs. B thinks dinner will be served shortly and declares she is not hungry. The nursing aid tells her dinner will only be served at five. Mrs. A again asks if I can free her. I ask the nursing aid whether Mrs. A has fallen or something like that. She answers: "No, but she always shuffles and her knees seem to give way and she's very restless." During these past few weeks, Mrs. A has always been like that: very troublesome, but I have never seen her fixated before. It certainly doesn't make her less restless. She keeps pulling my arm and now and then loudly moans.

The nursing aid simply says: "It's very quiet in here now, isn't it?" I answer there aren't many people present. She answers nobody is obliged to stay in the ward. Puzzled, I look at her, since it is a closed ward and no resident can leave when he or she wants to, but the nursing aid tells me one of the physiotherapists took some residents to the cafeteria upstairs.

The nursing aid seems to intend to serve Mrs. A's dinner on the little table that fixates her. When Mrs. A asks her to set her free, she first pretends not to hear and after a few times, says it must be very comfortable, to have a table just for oneself. I keep silent, but this situation makes me very depressed and nervous.

Mrs. A becomes more and more agitated and desperate. She rightly doesn't believe me anymore when I tell her she will be loosened shortly. Mrs. A breaths heavily and trembles more than usually. Then another nursing aid comes in. She takes away the fixating table and accompanies Mrs. A to the dinner table. Mrs. A has put all her force and energy in trying to move the fixating table and now can hardly walk. I had intended to stay another hour, but I feel my observations are coloured too much by my annoyance with the first nursing aid. I tell everybody goodbye and leave. [8]

7. Emotional Involvement with Residents

It sometimes was very hard not to get too emotionally involved with residents and not to get too affected by the cruelty and severity of the illness that struck them. Dementia is a very threatening disease. It could happen to anyone, regardless of class, education or past. Everyone entering a nursing home ward for people suffering from dementia, is confronted with the transitoriness of the human body and the human mind, or at least part of it.

Mrs. C greets me at the door. Usually Mrs. C is very confused and it is hard to have a regular conversation with her. She also seems to have grown fond of me during my visits to the nursing home ward. She now asks how I'm doing. I answer I'm doing very well, thank you, and reply with the logical question of how she is doing. "Well," she says, "I think I am dementing a little. You know, mentally getting worse. And I see it in my face too, when I look in the mirror. Do you see it too?" For a second, I don't know what to say or do and then, since she is asking me an honest question, I decide to answer in an honest way. "Yes, now that you are pointing it out to me, it is a little

> visible." "I know, and what do I have to do to make it a little better? Do you know?" I answer: "No, I'm sorry, but I don't. Maybe you will feel better after a good night's sleep. Sleep always seems to help a little." "Yes, that is possible. I live here now, you see? In number five. And next to my door is a little frame with a poem. I wrote it." I had noticed the poem before, it goes like this:
>
> Look with your present eyes
> into the clear white
> glass of the mirror
> not as you were; but as you are
> it's like you read a book,
> page after page
> and soon the last one
>
> It is signed with a phonetic version of Mrs. C's initials. The fact that it was written by someone with dementia gives it an extra dimension. I tell Mrs. C I like the poem. She says she's a rather poetical soul. I then ask her if she likes reading poetry too and she says yes. "I would have liked to make it my profession. It's quite simple, but that's how I am." I tell her that it can't be that easy to make poetry your profession. "No," she says, "and now I am far too old. Did you know I live in number five?" [9]

Some situations that were very shocking the first time I was confronted with them, became quite ordinary after a while. That could also have influenced my observations and their comparability. In the first ward I visited, I was confronted with quite explicit sexual advances by one of the male residents. Although the literature on dementia had prepared me to this in a certain degree, it was still a shocking experience. It happened again in another nursing home later on, but I was a lot less shocked. [10]

Time and time again, there is an ambivalent relationship between the observer and the observed: professional and personal at the same time. The success of the research at least partly depends on the degree to which I succeed in building a personal and at least trusting relationship with the informants. But the line with getting too emotionally involved is extremely thin.

> Good qualitative researchers must be prepared to learn to be trusted in the setting: they must be patient and wait until they are accepted by informants; they must be flexible and resilient; and (...) they must be prepared to 'make fools of themselves' (MORSE, 1994, p.226). [11]

To illustrate this last bit:

> While a next inhabitant is helped into bed, Mrs. D enters the living room again, now wearing her sleeping gown. She has lost her teeth and accuses me of stealing them. She is quite angry. Mrs. E and her friend Mrs. F are sitting next to me and defend me. Mrs. D leaves in a state of anger. A nursing aid returns and asks me jokingly whether she also has clean me up too and put me to bed. I tell her I have just been accused of being a tooth-thief. She bursts into laughter. She tells me Mrs. D always forgets that her teeth are put into a glass with a cleansing product at night.

> After Mrs. G, Mrs. H is also put on the weighing chair. She is very afraid. When she is helped into her seat again, she cries sadly. I go up to her and try to comfort her and it seems to help a little. While I'm kneeling next to Mrs. H., Mrs. I shouts from the other side of the room to ask if I am the mother of that beautiful baby. The beautiful baby is Mrs. H and she is at least eighty years old. If I look like her mother, I should urgently go and buy some ointment against wrinkles. [12]

8. Consequences for Data Gathering and Data Analysis

Qualitative researchers often embrace "thick description", but forget that their ability to "tell it like it is" is biased by preconceptions, theoretical prejudices and emotions. "Thick description" should include these aspects as much as possible, since they are an essential part of "telling it like it is". What I observe and experience is influenced by who I am and by what I have read and written before. [13]

Qualitative research in recent years has experienced a "crisis of representation". Skeptical postmodernists suggest that "truth" is necessarily relativized or even impossible and that, by consequence, scientific inquiry is impossible, too (GUBRIUM & HOLSTEIN, 1997, p.92). But while I agree that my "story" is different from another researchers" "story", I do not want to give up on reality. Fundamentally, I think that social phenomena exist not only in the mind, but in the objective world as well, and that there are some lawful, reasonably stable relationships to be found among them (HUBERMAN & MILES, 1998, p.182). In the age of postmodernism, qualitative and other researchers, must face the challenge of striving for empirical description of the social world and for scientific analysis of these descriptions while trying to answer the pertinent questions postmodernists ask. [14]

All of the problems mentioned in the previous paragraphs, relate to the idea that the observer is in this social world of the nursing home ward, but not of it. It leads to fears and uneasiness (FIELDING, 1993, pp.160f.), but at the same time this sense of marginality seems crucial for the success of the work. If I were completely part of the social world of the ward, I would probably not see a lot of things and I would hear other things in a different way and from a different perspective. I did not think I could avoid any of the problems mentioned, but I tried to take them into account by not only writing down what I observed, but also how I felt and what I experienced in different situations. By not pushing these problems aside and by making them explicit, I hoped to make my descriptions "thicker" and my analyses better. [15]

While analysing the data I also coded the parts that described my own feelings and experiences. I believe this allows me to make more subtle interpretations of the social world I observed. For the same reason, I also fully described my flow of thoughts during the analysis. I wrote down how I thought things were at one point, why I thought so and why I changed my mind. I do not think another researcher would come to completely different conclusions, but I agree that another researcher probably would come to conclusions similar to mine in a partly or completely different way. By making "my way" explicit, I (maybe naively) hope to

make a contribution to answering postmodernist questions about the crisis of representation. [16]

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