


Training Actors' Knowledge of the Lived Experience of People With Advanced Dementia

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Abstract

Do professional actors playing someone with dementia in training situations have knowledge of what it is like to be someone with dementia? And what knowledge? In preparation of a phenomenological study into the experience of people with advanced dementia in residential care, we interviewed four of these actors. Reflecting on their own experience with people with dementia and other experiences in their life enabled them to explore and find a reservoir of movements, gestures, postures, gazes, emotions, and responses from which they draw during their play. This reservoir is confirmed and refined in their playing persons with dementia. Their preparation, experience while playing, and reflection, validated by the response from caregivers, family members and people with dementia, make their knowledge as near as we can get to the experience of people with advanced dementia. Taking in this knowledge contributes to a larger repertoire to draw from in practising moral imagination.

Keywords

alzheimer's/dementia, communication, ethics, nursing, quality of life, long-term care

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What this Paper Adds

- Training actors have (embodied) knowledge about what it is like to be someone with dementia.
- Training actors playing someone with dementia actually play themselves, after putting themselves in a particular state of mind.
- Playing someone with dementia, actors may experience both a wall and being too open.

- Good care depends on connecting in an appropriate way – predictable, slow, soft, attentive to how the other seeks connection – but sometimes also on offering clear directions.

Applications of Study Findings

- Attentiveness to very small movements, gestures, changes in posture, et cetera, and responding to them is conducive to good care.
- Inquiring into the possible meaning of behavior that one may otherwise easily ascribe to the condition of dementia, and considering the possibility that it is a meaningful response to something one did before, is conducive to good care.

Introduction

This article presents the results of a small interview study, part of a bigger phenomenological study into the lived experience of people with advanced (that is, moderate to severe) dementia living in nursing homes. The bigger study was commissioned by an older persons care organization wanting to better understand the inner perspective of people with advanced dementia,

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especially those who are not so verbally coherent anymore. While there is a lot of research into the perspective of people with early-stage dementia and of partners and other relatives of people in all stages of dementia, that of people with advanced dementia has not been studied much (e.g. Mjørud et al., 2017). Interviewing persons with advanced dementia is difficult and problematic (Hellström et al., 2007; Hillman et al., 2019). We decided to closely observe several residents in their nursing homes, in a self-critical variant of shadowing called ‘spect-acting’ (Gill, 2011).¹ In preparation of this spect-acting, we interviewed several professional caregivers. Since we also wanted to mine other sources of knowledge about what it is like to be someone with dementia, we interviewed professional actors who play people with dementia, mainly in training situations. Such an interview study to gather knowledge of what it is like to be someone that the actor is portraying, is unusual, not self-evident, and easily criticised.

In the last two decades, the use of so-called Simulated Patients (SPs) has gained ground in healthcare. An SP is an ‘individual who is trained to portray a real patient in order to simulate a set of symptoms or problems used for health care education, evaluation, and research (Society for Simulation in Healthcare)’ (Lioce et al., 2020). The purpose of using SP methodology is often formulated in terms of cultivating empathy, compassion, and perspective-taking in order to improve the quality of care. SPs methodology is also used to teach and practice skills in dealing with challenging or disruptive behavior in patients. The contribution of the SP is: portraying a patient to which the trainee has to respond, answering the experienced behavior of the trainee with played behavior and, mostly afterwards, providing feedback.

An SP can be a professional actor or a trained amateur, although in the simulation literature there is some reluctance towards using professional actors as SPs. They are supposed to be oriented towards entertaining an audience, while an SP is supposed to serve the needs of trainee and trainer (Lewis et al., 2017; Liao et al., 2015). In the Netherlands however, professional actors are employed as so-called ‘training actors’. They are trained in working with acting techniques, stage and audience, and on top of that are specialised in playing a role in learning situations (Dutch Association of Training Actors, www.nvvt.nl).

There is a considerable amount of literature about the importance and effect of using SP methodology for improving care (Jack et al., 2014; Lewis et al., 2017; Myung et al., 2010; May et al., 2009; Park et al., 2011). Often this literature is about improving communication skills (Kaplonyi et al., 2017). There is also literature about the training of SPs (Keiser & Turkelson, 2017). And there is criticism, especially regarding the purpose of cultivating empathy, because the interaction with an SP is said to be rather a performance than an authentic encounter, with a power dynamics different from that of the interaction between care receiver and caregiver (Hanna & Fins, 2006; Perrella, 2016).

There are studies into the lived experience of SPs. For example Jarosinski and Webster conducted such a study,

concluding that SPs portraying mental illness sometimes have difficulties to shake off their role. But these authors did not interpret the SPs’ accounts as knowledge about what it is like to be someone with mental illness (Jarosinski & Webster, 2016).

In the literature, we find a concern about the accuracy and consistency of the ‘role portrayal’ of SPs (Lewis et al., 2017) – the simulation validity and reliability (Lioce et al., 2020). That is where so-called ‘subject matter experts’ come into play (Lewis et al., 2017). But who are these subject matter experts when it comes to dementia? We did not find literature about SPs portraying persons with dementia. How to know whether an SP portrays a person with dementia accurately? It can only be concluded from how trainees who have experience with caring for or living with people with dementia, respond and give feedback afterwards: do they experience the behavior and responses of the SP as accurate and helpful?

In our study, we wanted to explore the embodied knowledge that professional actors not only use but also gain when they project themselves into a person with dementia and expose themselves to care. Acting is a very physical process (Chekhov, 2017) and precisely that makes the actors’ embodied knowledge an innovative and rich source of knowledge. Their preparation, experiences while playing, and reflection, validated by the response they get from caregivers, family members and people with dementia themselves, makes their knowledge as near as we can get to the lived experience of people with advanced dementia. We expected that knowledge, together with that of professional caregivers, to be helpful to us in the spect-acting part of our study into the inner perspective of people with advanced dementia in nursing homes.

Methods

Research Question

The overall research question of the bigger phenomenological study was: ‘How is it like to be someone with advanced dementia?’ The research question of this interview study: ‘What can training actors tell about how it is like to be someone with advanced dementia?’

Participants

We, both experienced researchers, interviewed four actors whom we, led by what we became interested in, found in our own network as a knowledge institute in presence and relational caring (consecutive sampling). We started with a (male) stage actor who played a person with advanced dementia in his current show. Next, we interviewed a (female) training actor who plays several persons with early dementia for nursing students in examination situations. And finally, we interviewed two (female) training actors who play persons with advanced dementia in training situations, and play for and with persons with advanced dementia.

Procedure

We conducted semi-structured interviews. The stage actor and two of the training actors were interviewed by the first author, the third training actor by the second author. The interviews lasted between one and one and a half hours. The first interview, conducted after seeing the actor's show, was audio recorded. The subsequent interviews were also video recorded because the first interviewee started to act to check the accuracy of what he was saying. We did that because the interviewee's acting added something to their saying and we expected recording it to be helpful – and it turned out to be helpful – to the researchers in the bigger spect-acting study. The interview transcripts were first checked with the interviewees and then analysed by both authors using content and thematic analyses. A report of our findings was sent to them for comments and one of them responded in detail. Our general methodology, using just enough but extensively described cases, is elucidated and accounted for in [Timmerman et al. \(2019\)](#).

Ethical Considerations

As this is a non-interventional, interview study with adult non-patients without any dependency relationships with the researchers or the funding organisation, only informed consent of the four interviewees was obtained. This was done verbally and documented by audio recording the interview.

Results

In the interviews the actors related, often accompanied with gestures and postures, how they prepared themselves, how they played and what responses they got. They described their inner experiences while playing a person with dementia receiving care and while playing for and with people with dementia. 'Connecting with something in yourself or in your own life' appeared to be the key to what they were doing. They made it clear that they do not play someone else with dementia. They play themselves, after putting themselves in a particular state of mind. This state of mind can be interpreted as their personal entry point and calibration resource for the lived experience of being someone with dementia. In addition, they considered the responses of their audiences as a confirmation of the accuracy of their approach and as a source of refinement.

Discovering Dementia through the Body

The actors explained how, when asked to play someone with dementia, they started with informing themselves thoroughly. They read books and reports written by scholars and by people living with dementia. They watched documentaries and movies on the subject. They reflected on their own experience with family members with dementia. They exposed themselves to nursing home residents with dementia. In addition, they searched for specific experiences of their own as a personal access point to what it could be like to be someone with dementia. They

imagined themselves in situations they associated with the experience of being someone with dementia in order to discover and explore fitting physical movements, gestures, postures, gazes, feelings, and responses to other people. The interviewees described this as a complex process of intentionally acting out and bodily discovering what does justice to being someone with dementia. In this process a reservoir of movements, gestures et cetera emerges and is refined, from which they can draw while playing someone with dementia.

Personal Access

According to the interviewees, the actor's way of accessing the experience of being someone with dementia is always very personal. One of the actors, for whom language is very important, explained that he usually starts by imagining how he would experience losing language and meaning. In that process he feels an emotional response of fear within himself and learns how to deal with his fear. He then uses this experience in his play.

Another actor describes her method of mastering the role of a person with dementia as connecting to something she has seen in her father who had dementia, and recognizes in herself:

[One of her characters] has trouble with long sentences and complicated words. This causes a kind of explosion in her head. I can sympathize with such an explosion. I am sensitive to it myself. I expected it to happen now, now that I'm talking to a researcher. (...) It literally feels like an explosion of panic: he must think I'm super-dumb! (...) That whole package puts me in a state I can't figure out how to get out of' (Actor 2).

Yet another actor works with Chekhov's method of the 'psychological gesture', that has to become an 'inner gesture' (2017). She explains how this works:

'In what world do people with dementia live? Everything you used to be able to build on – your brain, your routine – falls away. My psychological gesture became 'falling'. This meant I let my inner person drop all the time: suddenly I would have no ground under my feet anymore... Then I would slip again, I would fall again... and again... And then I would try to catch myself again... What I like about this way of working is that I don't make up feelings. Instead I let a part of me – my body, my actions, my sounds – be colored by the emotions caused by that inner gesture' (Actor 3).

Stepping into the World of Dementia

While playing someone with dementia, the actors experience a loss of their sense of time, of being able to grasp what is going on, of understanding the responses of others. One of the actors describes experiencing a distance to the outside world that she cannot bridge by herself:

‘What I experience strongly is a form of confinement. In the body I live in. As if there’s a wall between me and the people around me. As if a life is going on that is completely different from the life that is taking place in me. I can’t make the connection. I’m in a bubble’ (Actor 4).

Another actor, however, reports experiencing an openness to what comes towards her from the outside world, an openness that she cannot manage or organize:

‘People who are just lying on their beds in the foetal position, perceive everything. Everything goes right through them. They’re actually super-sensitive. Their sensors are everywhere and almost too big. That’s what I like to play with: the sensation that you can’t close your doors anymore’ (Actor 3).

The interviewees also use the image of a clown to characterize both the behavior of someone with dementia as well as a way of getting on with people with dementia. The stage actor explains:

‘It’s like being a clown, being in the here and now, where in every moment everything is new, and you say ‘yes’ to everything’ (Actor 1).

In nursing homes, elder-clowning is used to improve dementia care, especially for people with Alzheimer’s disease (Kontos et al., 2017). One of the training actors explains how she uses this method to connect with people with advanced dementia:

‘The clown enters the world of the other. The clown himself fails and does not let the other person fail. The clown has no complicated storyline, but stays in the here and now, in a very sensory way’ (Actor 4).

While Receiving Care

While playing someone with dementia, the interviewees experience good care, care that is attuned to and benefits the other, to depend on connecting in an appropriate way. Approaching, making contact with and touching can be too unexpected, too fast, and too loud. When not understood, being treated and encouraged to collaborate can be very unsafe. Connecting requires stepping into their world, their sense of time, their perspective:

‘I played a lady who called her husband’s name all day. I asked the students what this lady needed. And I said [as the calling person]: “That someone is going to call with me”. When one of the students did that, it felt like, for a moment, my little bubble was getting somewhat bigger. It felt good that somebody was really willing to enter my world’ (Actor 4).

Entering the world of persons with advanced dementia, according to the interviewees, may require letting go of your

rouines, feeling and enduring your own uncertainty, and improvising. Connecting also requires being attentive to how the other seeks connection with you:

‘I am convinced that people in a foetal position also try to make contact if I am willing to see very small movements, a hand that pushes the duvet up a little, for example, as a presence, as a response from the person who is somewhere there’ (Actor 3).

In their acting the interviewees experienced that their way of making contact or temporarily abstaining from contact is not always noticed. Several of the actors pointed out the importance of paying attention to posture, muscular tension, and gaze. On the other hand, the interviewees report they sometimes get disoriented in their acting because the caregiver is offering too little direction. It is always worthwhile, according to them, to ask oneself what has happened in the interaction when someone with dementia shows certain behavior: is it an indication of feeling unsafe, dropping out or relaxing?

‘In my role I am very sensitive to patronizing or being spoken to like a little child. Then agitation arises (...). Or I pull a very tight mouth. I then get out of contact: I kind of fall asleep or stare ahead. I’m not being taken seriously; I don’t matter anymore’ (Actor 2).

Responses

Actors get responses from their audiences: during the show or training session, while pausing to discuss with the audience or trainees their mutual experiences, and afterwards. Often the actors receive responses of recognition, approval, and emerging insights, by both formal and informal caregivers. When acting for and with people with dementia, the responses are sometimes very tiny, physical ones. They vary from affirmation to joy and a request for more. The actors take these responses as a confirmation and as a resource for adjustment and refinement.

Discussion

How do we know that what the interviewed actors told us, actually says something about what it is like to be someone with dementia? The answer is: we do not know, but we have strong indications that it does. The interviewees reported that what they do and show is recognised and appreciated as helpful by people living with or taking care of people with dementia. The key factor appears to be: to search for something within yourself or from your own life, that you can connect with. Is that enough? Certainly not, and you will have to remain alert and inquisitive: your experience might not be what the other is experiencing (Vanlaere et al., 2012). An important way in which the knowledge of these actors is relevant to good care is that it contributes to the repertoire of

images, metaphors and frames to draw from in practising moral imagination, the ‘ability to imaginatively discern various possibilities for acting in a given situation and to envision the potential help and harm that are likely to result from a given action’ (Johnson, 1993, p. 202).

Is there something to say about what it means, in essence, to be someone with advanced dementia? There is one observation that made us think. One actor talks about a wall between her and others; another actor mentions feeling defenceless against what is coming from the outside world. This may be an indication that the ambiguity given with the everyday living and living together of human beings is amplified or heightened by the process of dementia. Experiencing a wall on the one hand and being defenceless on the other, may be part and parcel of what it is like to be someone with dementia. This is a subject for future research.

What did we learn from this study for the bigger, spect-acting study? We became more aware of the relevance of looking at very small movements, gestures, changes in posture, et cetera, and of looking for a meaningful response in behavior that one may easily ascribe to the condition of dementia. In the analysis of the empirical material of the spect-acting study, the idea of heightened ambiguity as a core element of what it is like to be someone with advanced dementia became substantiated. We will report on this in another article. The main limitation of this study is the small number of interviewees in proportion to the complexity of living with advanced dementia. Nevertheless, this study delivered conjectural knowledge that was useful to the spect-acting study and was confirmed, to a certain extent, by the findings of that bigger study.

Conclusion

Based on the four interviews, we conclude that training actors indeed have specific (embodied) knowledge about what it is like to be someone with dementia. Heightened ambiguity may be a core element of what it is like to be someone with advanced dementia. This knowledge, however conjectural, is relevant to good care, care that is attuned to and beneficial for the other, mainly because it contributes to the repertoire to draw from in practising moral imagination. According to the interviewed actors, it is worthwhile to take good notice of what has happened in the interaction before someone with dementia showed certain behavior. That behavior may well be a meaningful response to the way that person perceived and interpreted one’s acting towards him or her.

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Ethical Approval

As this is a non-interventional, interview study with adult non-patients without any dependency relationships with the researchers or the funding organisation, only informed consent of the four interviewees was obtained. This was done verbally and documented by audio recording the interview. This study is part of a bigger phenomenological study, including a spect-acting study of residents of nursing homes. Regarding this spect-acting study, the Medical Research Ethics Committee of the University Medical Centre of the Utrecht University confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply and that therefore an official approval of this study by the MREC of UMC Utrecht is not required under the WMO (Reference Number WAG/mb/18/026473).

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Note

1. A publication reporting the spect-acting study is in preparation.

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