Between the Lines
Communication with People with Dementia in Creative Movement Sessions

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ABSTRACT This article explores the various ways of communicating with people with dementia during dance sessions and how creative movement can support people to create meaning in the moment. The following did not originate in conventional research but is a reflection on my work as a dancer in healthcare. I took notes about my observations for my own development. After some time I felt the need to dig deeper and search for theories affiliated to my thoughts and find out more about dementia.

KEYWORDS: communication, dance, dementia, identity, kinaesthetic empathy, touch, well-being

My Approach

I strongly believe in dance as a tool to unlock channels for self-expression and to strengthen self-esteem, wherefore in my dance sessions I give guidance for participants to find their own movements based on structured improvisation. I work on body awareness as well as social skills like how to connect with people and the environment through listening and talking with the body. Verbal or movement input by participants is taken with respect and what they say or do is considered important in my sessions.

For me, the wish to work in healthcare has to come from the genuine interest to get to know another human being and the complexity of his or her life; to be ready to accept and respect participants without judging them is the foundation of going into every session. Naomi Feil’s validation principles when working with old and confused people are similar. She talks about accepting emotions of the person who cannot tell you anymore what feeling she/he has in order not to stress them and try to dive deeper into their inner world to understand them and be able ‘to walk in their shoes’ (Feil 2002).

It may sound very simple and a common thing to do, but actually it is not that easy. It surely depends on what role you can take in your job. I know, I have a big advantage compared to nurses or carers in institutions, who are there every day for many hours and have to make sure that the basic needs, like hygiene, food or medication of their clients are covered. I, as a trainer or artist, can come in once a week for an hour and my time is devoted to the emotional needs of the individual. Teepa Snow, an American expert on dementia care explains this in relation to Maslow’s (1987) hierarchy of needs. She underlines that care often stops at the bottom two needs, the physiological and safety needs and does not reach out to the need for love and belonging, self esteem and self actualising (Snow 2011). With creativity you start right at the top end of the hierarchy.

My practice is very much influenced by Alito Alessi’s and Karen Nelson’s method of DanceAbility that allows people with different abilities, backgrounds and needs to come together and dance. I am convinced that this way of interacting supports wellbeing in general but can also have a special impact on people living in a healthcare environment. These are people who often have lost ownership over their lives; usually somebody else decides when they have to get up, get their food, how they can decorate their ‘room’ or what they are allowed to spend their money on.
Their voice does not count anymore; these people live in a parallel world to our society because they had an accident and suffer from a brain injury, got old and have Alzheimer’s or have a mental health problem and just do not fit anywhere. Erich Fromm wrote in ‘Revolution der Hoffnung’ [Revolution of Hope] that ‘Im Augenblick, wo wir stillstehen, fangen wir an abzusterben’ [The moment we stand still we start to die] (Fromm 1981). In the context of healthcare, I see this statement as a call for more creativity in this environment to fill it with life and make the people living or spending a lot of time there emotionally and physically feel alive. Staff engagement can lead to a new way of connecting with their patients and understanding them better, but also to more satisfaction and fun during their working hours. One of the main outcomes of a creative movement programme is that it activates people; it lifts their mood because they have a holistic experience that involves body, imagination, emotions and they interact with others. Participants create their own dances during a workshop, they get empowered to be proud of their movements and inventions rather than reproducing the facilitator’s routines. I am interested in an individual approach, looking at the strengths of each person and developing something around it, not so much in trying to create uniformity through choreographies where each dancer is supposed to learn the same routine and look the same.

I want to highlight once more the positive effects of dance training: strengthening and stretching of the muscles, work on balance, fall prevention, training of Activities of Daily Living (like reaching out for something – a cup), cognitive training, coordination, release of ‘happy hormones’, self-esteem support, learning something new, socialising, stress reduction, creativity promotion, channelling of emotions and releasing memories. The advantage of dance compared with, for example, physiotherapy, where therapists work closely with movement and usually train a lost skill through repetition, is that we can give people the freedom to follow their needs in a specific moment. They learn on many different levels since conducting a movement is combined with an emotion, the position in a room or to another dancer, the sense of time and the dynamic and rhythm. It is the playfulness that supports learning.

Bourdieu talks about incorporated cultural capital, which describes all the knowledge an individual has cultivated in a life. The main investment that one has to make to be able to learn is time and this is connected to the social network. The people around you need to give you the freedom and time to learn something new; like parents their children or a boss his/her employees (Jurt 2003). In a care situation, usually it is the doctors/nurses or the relatives who decide if the person having a disease is allowed to learn something new or not. As many people have no contact with the arts and especially not to movement after they have left school, they cannot imagine how this could be fun or make someone feel good. This lack of experience is connected to fear and inhibitions that a dance facilitator in a healthcare setting has to deal with on a daily basis.

I mix my dance sessions with a variety of other creative tools in order to increase the chance of reaching the participants in some way, which is similar to the method of Expressive Arts Therapy by Diana Halprin, without claiming therapy. In this article I will focus on one-to-one and group sessions I lead in Day Centres or long-time hospital wards for people with dementia. Usually patients on hospital wards are supposed to stay a short time as a transition solution only, but for many it seems to become their home.

Dementia

The definition of dementia given by the World Health Organisation is as follows:

Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected.

Dementia is not simply dementia. Is has as many faces as people who get diagnosed with it. It has to be distinguished from other conditions that might be more temporary or may be treatable, such as depression or alcoholism. In contrast, neurodegenerative diseases like Alzheimer’s disease, Parkinson’s disease, Lewy Body or fronto-temporal dementia amongst others may be treated symptomatically but progress until death (Bourgeois and Hickey 2009). Besides the organic reduction of the brain functions, which depends on the type of dementia, this illness provokes very individual reactions depending on the past, memories, skills or interests people have or had and other accompanying health issues. Everyone can get it, it does not matter how much knowledge one accumulated during a life – but the more one knows the more likely it is that a person finds and learns new strategies to deal with problems. In order to communicate appropriately with people with dementia and support them in the best possible way it is helpful to know of the different stages they go through during
their illness (Reisberg et al. 1982), but it is important to remember that usually a disease does not progress as it is written in a book and often symptoms overlap or other illnesses add up and give an even more complex picture.

Communication

We communicate all the time and on so many different levels that it becomes quite impossible to be aware of all the information we transmit in a moment. Furthermore we do not know how a message shared is received and interpreted. We can only guess what the most appropriate way would be so the person we would like to share information with will be able to connect with that attempt (Myers and Myers 1973). Myers and Myers (1973) considered two forms of response to communication with our environment: interpersonal (with other people) and intrapersonal (with yourself), both of which can be trained through dance. My example is based on a DanceAbility class. The warm-up starts with a relaxation exercise and a journey through the body, which strengthens body awareness and the communication with the self. In that moment the practising person has their eyes closed and only follows their desire for movement. The second step is to become aware of other people in the group and relate to them through looks, mirroring movements and shapes or engaging with a partner or more people in a dance. We can practise how to open up, react and connect with the environment, find new perspectives and take in information that surrounds us. For a facilitator it is as vital to be as skilled in sending messages as it is to comprehend information provided by a group. To listen actively to what is being said and to not judge but to take the message and feed it back to the group is a valuable tool.

In ‘The Presentation of Self in Everyday Life’ Erving Goffman (2001) discussed what happens when social interaction is disrupted. He talked about three different levels that are affected by an unexpected move during an interaction: the interpersonal, the institutional and the personal irritation. I want to use that idea to look at the interpersonal level and use the interaction between a person with dementia and a carer as an example. Here it will always come to some sort of disruption. In that dialog, everything is possible and cultural codes disappear; for the carer there is usually not much to hold on to if he/she tries to stick to the norm. Therefore, various guidelines and methods have been developed to support that dialogue, such as Naomi Feil’s (2002) Validation, which tries to engage with the person and step into their world. However, even with all the tools you can learn, you cannot be prepared for all the surprises and you need to be flexible and really creative to be able to find solutions in the moment when something difficult or unexpected happens.

When I step into the world of a hospital ward as a dancer, I am an exotic creature for many of the people working there. I can see their doubts, when I say I am here to dance with their patients. This outsider role gives me the chance to interact in my way, because they think I am eccentric anyway. I do not need to follow norms as much as a nurse, who is very much linked to the rules of the institution. So I can walk the hallway up and down with John and sing a song for him out of the blue to which we start to dance.

Emotional Levels and Authenticity

Another very important point for me in leading a session is authenticity. People with dementia need to replace their strategies to understand the world; when words and faces do not make any sense anymore they become more aware of emotional triggers. They will be able to notice if a person or a situation makes them feel good until a very late stage of the disease, although they cannot tell you why anymore. Bryden, an Australian woman, who was diagnosed with dementia at the age of forty-six, described her journey as one to the core of the self, where the exterior world and values become less and less important (Bryden 2005). When leading a training session it is important to be clear in what you say and do and mean it; irony and metaphors can be hard to decode.

The way I, as a facilitator, act or react cannot come from feeling pity or seeing only negative things that happen in the participants’ lives. The first time I saw a long-stay ward I was shocked by the sterility and sadness there, and that was the mood I brought with me while working there for the first few weeks. I then decided that this had to change. I wanted to be totally positive for the service users to bring them some happiness from outside. This however turned out not really to work for me, because I am simply not always happy and it felt fake. So I thought: ‘Why should I play a masquerade and present them a perfect me without any problems, while they are themselves with all their limitations?’ This was when I changed my approach into an authentic one that actually gives me the freedom to share how I feel. The honest giving and receiving makes this job so beautiful to me; the experience of being fully in the moment, because all
my senses are alert to what is happening around me, to be able to invite people to come on a creative journey with me.

**Touch**

In care institutions, the physical contact people get is mainly for hygienic, medical or therapeutic reasons; touch is used to resolve a problem, like taking bloods, transferring someone from bed to a wheelchair, putting clothes on, trying to make body parts move again and so on. There is not much affection in these environments. It is humane treatment but we deprive people from a simple human need and take away a possible form of communication. Barbara Goldschmidt intensely explores touch using hand massages as a form of communication with people with dementia and in end-of-life care:

> When you learn to use touch to communicate, you may discover an alternative to words that can satisfy a deep need. When someone is elderly, chronically ill or approaching the end of life, and everyday roles and abilities are lost, caregivers are naturally drawn to non-verbal ways to communicate. They will attach more significance to the flicker of light in the eyes, the rhythm of breath, or the squeeze of one’s hand to indicate awareness. (Goldschmidt 2012: 15)

There are many different situations to work with touch as a dance facilitator. The way to touch a person with dementia starts with the approach: it is so important to make sure, as far as it is possible, that the person to be touched realises you are there. Some other contact has to be established before, instead of surprising someone by reaching out quickly to take their hand. You would not want to scare the person being touched: maybe they are in their own world, seemingly sitting in an armchair on a ward, but in their mind and their reality they are wandering around in a forest. My aim, then, is to get a moment where I can see that the person I try to connect with is ready to share some time with me.

For elderly people it is lovely to organise a tea dance event where they can dance alone, as a group or in couples. Through couple dances, a very intimate atmosphere can be created in a room full of spectators. You build up a little bubble where only two people exist for a moment. This can make you feel important. You need to tune in with another person to make sure that you find the same rhythm and steps that give them enough stability to feel safe. Music supports reminiscence and can provoke memories of a fun night out in a dance hall with friends or a partner.

As DanceAbility has its roots in contact improvisation, many of the exercises are geared towards partnering and group work; it is possible to adjust them to the needs of a group and use touch or not but still train an awareness or attentiveness towards another person or the space. People have inhibitions to touch another person because they are not used to that form of contact. With games and different exercises, we manage to turn touch into a natural form of contact, where it happens as an outcome of a given task. Individuals might not like each other. They might not want to be close to each other. Again, it is about observing the group and individuals to understand what is appropriate in the moment and what the group could need.

**Kinaesthetic Empathy**

Another way to communicate can be through empathy. Hayes and Povey (Hayes and Povey 2011) talk about kinaesthetic empathy as an essential skill when working in dementia care. They suggest accompanying someone while breathing like he/she does and moving the way the other person does in order to see and understand their perception a bit better. Kinaesthetic empathy, or proprioception, is discussed by performers, choreographers or performance studies in terms of audience engagement, but it was first implemented in physiological studies of the late nineteenth century and, since the 1990s, it is referred to as ‘mirror neurons’:

> These neurons fire when the subject performs an action, and they also fire when the subject sees the action being performed. Thus as we watch someone moving, motor circuits in the brain are activated that do not necessarily result in visible movement but nonetheless rehearse that movement. (Leigh Foster 2008: 54)

This is a crucial fact explaining the value of working as a dancer in a healthcare environment. Often, you meet people who would not show noticeable reactions and then suddenly smile or lift an arm as you do. This means that something is happening with them. Their mind is exercising for them while they are watching. They might not even be aware of it, but the mind sends the information and people remember situations or movements they have been used to doing in their lives. I also got feedback from a wheelchair user that it is relaxing to watch a performance. I think it is fantastic that people who might not be able to move can benefit from somebody else moving, like a relaxation of the muscles or calming down of the breath. On the contrary, it is possible to infect people with
excitement, which I believe transmits through passion; it jumps over and encourages participants to get engaged. If you smile, the brain of the participant fires the same neurons and chemicals and will feel good in that moment.

Identity

‘Who will I be when I die?’ is the title of Christine Bryden’s book about her life after she got the diagnosis dementia. By sharing her story she tried to deal with the fear of losing herself, and confront a future without identity (Bryden 2005).

How can I support people to create some sense of identity as a dancer? It can happen that with dementia the nervous system is damaged and the cells all over the skin cannot inform the brain anymore about the spatial position of the body. People lose their identity; not only because they forget their biography but sometimes also because they cannot recognise their face or sense their limbs any longer. In that case movement can be very supportive to activate memory and give meaning to people. An old woman could feel comfortable by stroking and swaying her own hand, recreating the emotional memory of her role as a mother (Feil 2002). To be able to lead the participant to that stage of biographical information is helpful for a dance session. But the same body memory also holds risks. As a facilitator you never know what kind of movement triggers what memory, so it can happen that negative emotions evolve. If you take that emotion seriously, and do not ignore it, you might be able to help that person to solve an inner conflict in that moment.

George Herbert Mead saw communication as a permanent tool to structure society and make us aware of ourselves. Identity is therefore created through interaction with others (Abel 2006). In healthcare many people just sit around and watch television or stare into space because they are not able to socialise any longer; some might have decided not to be interested in others any more, but mostly human beings have the need to be addressed by others. As I mentioned above, it can also be seen as part of developing our identity. Working on a physical level, because your training partner does not understand the meaning of words or the concept of exercising, or wanders about continuously, can be the only chance to connect with someone. For example, I decided to feed John’s gestures and movements back to him, to support him in sensing himself. He is not able any more to take on my role in his head; Mead sees the process of putting yourself in someone else’s position as the pre-condition for identity. Mead defines ‘I’ and ‘me’ as two different parts within a person. The ‘I’ stands for the recreational, impulsive and creative part in people that can never be totally socialised. The ‘me’ is the reflective part in us that realises how people react towards us and which roles we take on in different situations. Therefore the ‘me’ is creating allocated identity. To be able to reflect on something you need a certain amount of experience that you can save as memories and learn from. Looking at a person with dementia, I would affirm, he or she might lose the skill to reflect on a situation or an action earlier than the ‘I’ – the creative and impulsive part, which goes perfectly with the arts and especially dance improvisation.

Conclusion

I do not claim dance as the only way to reach people with dementia, but it is a fantastic one that is not yet exploited enough in healthcare. I am sure that the main factor to support someone in their wellbeing is to devote time, to be with him/her and let them be, not to correct them all the time, and to respect them, although they might eat tissue paper or tell you that they are friends with Elvis Presley.

The movement approach is a process of trying to communicate with another human being on different levels and not only on a verbal basis. It is a path that you go together and learn about the other. You have to use every piece of information you can get to support them in creating meaning for a short period of time. Sometimes, even, you will have to give up when the person decides today he lets you go, accompanies you to the door and very nicely makes it clear that he will go the other way.

Elisabeth Zeindlinger, born in Linz/AUT, teaches DanceAbility, coordinates cultural projects like dance events or exhibitions and was trained as a facilitator for people with dementia by M.A.S Alzheimerhilfe. She holds a degree in Anthropology. Her thesis analysed if the existence of a care home for approx. 350 people with learning disabilities in a small town of 6.000 has influenced the infrastructure and thinking of inhabitants. She has been living in Ecuador working in a health centre with women, studied in Finland and stayed in Northern Ireland for a couple of years after receiving a grant from the Austrian ministry of culture.
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