

# Embodied meaning-making in the experiences and behaviours of persons with dementia

## BACKGROUND

► Dementia affects the brain and make people vulnerable as memory, communication and orientation is impaired, in particular at the stage of severe dementia. Our assumption is that despite these impairments persons with dementia are as much in need of meaningfulness in life as any other human being. The challenge is how to describe meaningfulness considering common theories, and the research on this subject is scarce. In the understanding of meaningfulness we lean on Schnell's definition "as a fundamental sense of meaning, based on an appraisal of one's life as coherent, significant, directed, and belonging" (Schnell, 2009).

## AIM

► The aim of the study is to explore how meaningfulness appears among the patients with severe dementia within a hospital context.

## METHODS

► The data were collected by participant observation in a hospital bed unit over a period of four months. Ten patients with severe dementia were included. The researcher participated in daily activities like meals, walks outside, sing-alongs, exercise, or just spending time with the patients, either individually or in groups. The observations were noted and written down in fieldnotes and analysed.



## RESULTS

► Analysing the data material, we find narratives from everyday life that carries with them existential themes communicated through the body's actions, reactions and emotions. We label these narratives as *existential dramas*. These existential dramas show that meaning-making happens when a person's history connects to the present situation through the body. When participating in baking Christmas cookies the body remembers how it is done, giving an experience of self-actualization; "I am significant to others". Being situated in a social context and reminded of one's own forgotten abilities like writing poems or singing in a choir, gives an experience of life as connected. The existential dramas are examples of *embodied meaning-making* that connect to oneself and allow to grasp and cope with the environment and others.

### Existential drama I

Life is connected – a poem reading connects to previous cognitive function. A sense of coherence.

*Gerda has severe dementia. She is very cautious, often apologizing to people around her saying "I can't do anything anymore" or "I don't know what to talk about anymore". I meet Gerda in the corridor when she is on her way from the living room to her bedroom. "I am so sad today," she says. She has just been helping to prepare some waffles for the "chaplain's hour" later. We agree that Gerda will lay down on her bed, and that we will tell her when the chaplain arrives in about half an hour.*

*"Chaplain's hour" is once a week. The table in the living room is decorated with a nice tablecloth and some neat crockery. Patients, nurses and the chaplain are drinking coffee, eating waffles, chatting and singing songs together. The chaplain's hour is a popular change in the everyday life at the ward. It is not a devotional gathering. We are singing folk songs, hymns, religious and non-religious songs. Some of the songs may be related to the current season of the year.*

*A person from the staff brought a poem that Gerda had written 15 years ago. The poem had been printed in a book. The chaplain reads Gerda's poem. The poem is about the significance and power of words. Gerda is sitting with her back straight while listening to the Chaplain reading her poem, and she is smiling.*

*"I cannot believe that I have written this poem" she says shaking her head. For a moment the anxious old woman was calm, happy and proud of herself. We told her that her son brought the poem to us. "Did he really?" she answered and smiled even more.*

### Existential drama II

The body remembers – experience of self-actualization.

*The other day, Gerda had been very anxious in the morning. Three times during breakfast she left the dining room and went back to her room.*

*After breakfast, baking traditional Christmas biscuits was on the agenda. The dining room was cleared and prepared for baking biscuits. Pastry was already prepared in a bowl at the table. Gerda was invited to come and bake. She first excused herself saying "I don't know how to bake biscuits anymore." Eventually, she decided to come along.*

*Carefully entering the dining room, she noticed the pastry at the table. She went to the table, picked up a knife and started to cut the pastry into smaller pieces. I put an apron over her head, and she tied it, without looking, with a knot on her back within seconds. The anxious insecure woman, was now in charge and in command of baking biscuits. Together with one of the other patients, they rolled, sliced, put the biscuits on a baking tray, brushed with eggs and sprinkled with chopped almonds. Within 15 minutes more than hundred biscuits were ready for the oven.*

### Existential drama III

Participate in community – belonging and self-actualization.

*Emma has severe dementia. She has trouble speaking but can express herself in short sentences of two or three words at a time. Frequently she is not able to remember the words she wants to use. Several years ago, Emma had been singing in a choir for many years.*

*One afternoon in December we went together with one other dementia patient and a nurse to the cafeteria at IKEA. This was on the St. Lucia day and an invited choir performed a Lucia celebration in the cafeteria. As we sat drinking coffee at a table in the cafeteria, the doors opened, and the choir entered the room in a procession wearing white robes and each holding a candle in their hand. They were singing the Lucia hymn as they entered the room.*

*As the choir entered the cafeteria, Emma stood up from her chair and almost in a spellbound manner watched and listened to the choir in the procession. Emma started to hum along with the choir.*

*After finishing the procession, the choir held a little concert in the cafeteria, singing a few Christmas carols. Emma was standing at the floor a few meters in front of the choir. She was humming along with the choir and slowly moved the body to the music. This was in a cafeteria with a lot of people, so nobody took notice about her behaviour. After a few songs, something amazing happened: Emma started to hum the alto voice to one of the carols.*

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### References

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