Film Review


Aagje Swinnen
Maastricht University
a.swinnen@maastrichtuniversity.nl
Film Review


Aagje Swinnen
Maastricht University
a.swinnen@maastrichtuniversity.nl

The Dutch documentary *Ben Jij Bij Mij/Are You With Me* (2021) is a first collaboration between visual anthropologist and filmmaker Mark Lindenberg and psychologist Sophia van Ghesel Grothe. It features Joke van den Broek, a 92-year-old former schoolteacher and van Ghesel Grothe’s grandmother, over a period of three years in which she moves from her family home to a long-term care facility because of Alzheimer’s disease. *Are You With Me* is the winner of the 2021 Ageing and Visual Anthropology (AVA) Award and the 2022 Mantas Kvedaravičius prize, awarded at the European Association of Social Anthropologists (EASA) Conference in Dublin. It distinguishes itself positively from many documentaries about Alzheimer’s disease and related dementias in that it carefully moves away from the story of doom and gloom that most films tell to a story of connection and entanglement. This is especially meaningful because documentary films are all-too-often watched for their mimetic quality, thereby ignoring directorial choices during filming and montage that define what narrative is being conveyed. *Are You With Me* invites discussions about the affordances and limitations of dementia representations in the film medium (Deng 2023; Medina 2018) and is an interesting case study to analyze not only in scholarly settings but also in educational contexts, such as medical and nursing schools.

The documentary starts with the voice of the granddaughter, Sophia van Ghesel Grothe, painting a picture of Joke while a compilation of archival images is being shown. The voice-over characterizes the grandmother as an “imaginative woman” and “genuine storyteller” who talks to everyone and everything ranging from the woman next door to the spoons in the drawer. Sophia ends by raising two questions that frame the narrative: “Would my grandmother lose her spark with the fading of memories and her independence? Who is she without her story?” Watching the rest of the documentary in which we see Joke interacting with her family members and her surroundings at large quickly convinces the viewer that the answer to the first question is a firm no. The second question is more provocative. It not only assumes that life is a story and that people are storytelling creatures or *homo narrans* who give meaning to and shape the world through the narratives they tell. It also assumes that a person who lives with Alzheimer’s disease no longer has a story and, therefore, risks losing her personhood or self. It is one of the greater achievements of *Are You With Me* that it largely debunks this assumption by showing that a story does not need to be coherent or consistent to matter nor that a story or a self is located solely in an individual’s mind (Lehmann, and Synnes 2023).

In recent years, the medical and individualized view of dementia as a disease of the brain is gradually being replaced by a disability studies perspective (Shakespeare, Zeilig, and Mittler 2019; Yoshizaki-Gibbons 2023). The latter does not position the person who lives with dementia as a problem that needs to be solved or managed in the absence of a cure. Instead, it points to the environment for falling short...
of understanding people living with dementia and for inadvertently contributing to their suffering. A disability studies perspective also aims to honor the voices and lived experiences of people who live with dementia and to promote social justice. A precursor of the disability studies approach is Tom Kitwood’s (1997) relational model which helps to assess exchanges between Joke and her family members in Are You With Me. The documentary includes several instances of what Kitwood called “positive person work” – exchanges that reinforce the protagonist’s sense of self and self-worth. Joke’s caregivers, for instance, encourage her to retell the story of her father teaching her the German song “So nimm den meine Hände” at the age of five or six. When Joke starts to forget the stanzas, she hums the tune of the song and family members help her fill in the words. This co-creation of the song enables Joke to deeply connect with her (grand)daughters, which clearly gives her joy. There are other encounters in the documentary in which caregivers respond to Joke’s rhyme and song with language play. These are complemented with non-verbal rituals, such as giving a kiss on the head, that establish continuous and reciprocal intimacy over the course of many years as the video footage shows. All these interactions stimulate the protagonist to fully tap into her specific communicative repertoire.

However, when Joke’s family tries to negotiate issues of risk and protection with their (grand)mother, especially in relation to the assessment of whether she can stay in her family home, some of their questions come across as rather twofaced. Questions such as “Why do you think you are here now with all your family around you?” or “What color is that cat, Grandma?” set Joke up for failure, as she cannot answer them with certainty. They establish a divide between who is neurotypical versus neurodivergent in the conversation – the former having the upper hand. Even the editing serves to debunk the voice of Joke. When she, for instance, claims to do the shopping and cooking all by herself, we see images from the diegetic present in which she mainly heats the meals that her children have prepared for her, juxtaposed with images of 1995 in which she still did the cooking in that same kitchen. The recurring nervous laughter on the part of the family members reveals that they feel uncomfortable when confronting their (grand)mother with what they perceive as her divergences from the truth. The viewer also experiences discomfort when watching this dynamic but finds relief in Joke’s resistance. She is quick to wittingly point out that one of her daughters positions her as a “disobedient child” or she claims that her daughters are just “more anxious” than her when they express their fear over their mother getting lost. One daughter cannot but admit that Joke has “no memory for negative things.”

Throughout the documentary, Joke’s caregivers oscillate between “talking sense” into her and letting opposing views coexist. Again and again, we see the (grand)daughters trying to sustain the mother they always knew. This becomes especially clear when one of the daughters informs Joke that it is time for a visit to the hairdresser because she “likes looking at a beautiful mother” – an expectation that surprises the protagonist. In a similar vein, another daughter cleans Joke’s nails and puts lipstick on her while explaining that she honors her mother’s wish to never become a “pathetic person.” Satisfied with her intervention, she concludes that her mother has become “absolutely Joke again” while the viewer might wonder whether this is also Joke’s own experience and desire. The struggle of those giving care to a person living with dementia is that they may spend too much energy on reclaiming a person as they were in the past and thus pay too little attention on who the person is becoming in the moment. This is why the relational model of dementia is increasingly complemented by the post-humanist realization that human beings are always part of agentic assemblages in intra-action with their surroundings (Jenkins 2016; Quinn & Blandon 2020).

People are not just entangled with other human beings like family and friends but also with their natural and material surroundings. In Are You With Me, the directors show that Joke knows better than anyone to express her connection with everything around her. She addresses her fridge with song and rhyme and engages in an imaginary dialogue with the microwave. But the real beauty of this documentary lies
in Joke’s conversations with the sun, flowers, plants, and trees, illustrating how she and these organic beings are teeming with life. In her exclamations about her natural surroundings, Joke demonstrates that voice and narrative do not exclusively belong to the individual but are distributed across different agents that together are one. Observing flowers and the fluff ball of a dandelion, she says:

They are very proud. Look how big we are and our beautiful color. Well, just look at me. I am all alone here. Look, you can see right through me, I am that thin. But I am still completely myself. … So, who knows I can see you again on a picture and that portrays a lot including you, yes. So, if I am not there anymore, I am still on such a picture. I like that.

Notice how the protagonist quickly changes from first to third person and from singular to plural. The existential concern of a flower that is fading in the wind merges with Joke’s reflection on her situation and on the significance of filmmaking as a documentation of their joint existence. She and the dandelion are forever entangled beings.

It becomes painfully clear that Joke’s routine of moving through the family house and the garden is disrupted by the move to the care facility with its brick facade and corridor in which to dwell. New connections need to be formed there but it remains unclear how this will be established. Joke and part of her belongings seem mostly out of place. She must rely on her family members to take her outside in the wheelchair and let her reconnect with nature. By the end of the documentary, the protagonist herself provides the ultimate answer to the framing question who she is “without her story,” the framing question of the film. Undoubtedly, Joke is a teacher, not necessarily in her former professional role but in her ability to pass on advice on how to live life considering the inevitable changes that come with age: “Life, you can always enjoy it, as long as you are open to everything changing.” Joke ends by thanking her granddaughter and filmmaker for “letting me tell you, in this way.” The main takeaway from this documentary is, therefore, the resilience of Joke herself and her lesson that “love, yes, that stays.”

**References**


