

## As Far as I Can Record

### Constructing the Representations of Living with Dementia in a Personal Documentary Film

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**Abstract** This account draws on my experience as a practitioner filmmaker documenting my father's experience of living with dementia. The scope is to analyze how the intimate relationship between me as a filmmaker and the people portrayed in the film shapes the construction of the visual representation of the experience of living with dementia. This reflection is placed in the larger frame of the cinematic and media portrayal of mental illness. Visual portrayal of circumstances that involve people struggling with mental disorders, calls for a particular awareness of the responsibility and accountability of documentary filmmakers who assume such endeavors. Personal audio-visual engagements have been viewed as a possible answer to the problem of representation raised by the ethnographic and documentary practice. They are part of a broader 'social movement that blurs the lines between public and private life' (Aufderheide 1997). Throughout the process, the filmmaker assumes interchangeable roles of both insider and outsider. The subjective position of the filmmaker subverts the aspiration to objectivity, realism, and precision of traditional documentary discourses. Drawing on my experience as a practitioner filmmaker documenting my father's experience of living with dementia, I discuss the methodological challenges that emerged during the process of film production. What are the cinematic strategies of reinterpretation, reconstruction, and understanding of self and otherness? How does such a level of access and intimacy affect the construction of the narrative of living with dementia?

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**Keywords:** personal documentary – mental illness – media – cinema

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This account draws on my experience as a practitioner filmmaker documenting my father's experience of living with dementia. It has been a decade since his diagnosis and my first recordings of him. Currently, the film is in the early stages of editing. Going through the footage over and over again has allowed me to revisit the decision-making process while filming on-site and to identify the factors that have influenced the content of the narrative and the narration choices. The scope of this paper is to analyze how the intimate relationship between me as a filmmaker and the people portrayed in the film shapes the construction of the visual representation of the experience of living with dementia. This reflection will be placed in the larger frame of the cinematic and media portrayal of mental illness.

Depictions of mental illness in documentary films call for a reflexive consideration of the

responsibility and accountability of filmmakers who assume such endeavors. Both fiction and nonfiction cinema and media have created harmful portrayals of mental illness. Personal audio-visual non-fiction films have been viewed as a possible answer to *the* problem of representation raised by the ethnographic and documentary practice decades ago. BILL NICHOLS (1991) has seen the emergence of personal documentaries as a political response and a potential solution to the debate about the power, authority, and legitimacy of creating representations of others. The proliferation of personal documentaries is part of a broader 'social movement that blurs the lines between public and private life' (AUFDERHEIDE 1997). Whether the filmmaker is in front of or behind the camera, whether one uses images from their personal archive or observes current situations from everyday life with the camera, wheth-

er one uses voice-over or different interview formats, in these documentaries the limit between public and private is constantly discussed and negotiated. The co(i)mplication, meaning 'both complex and interpenetration of 'subject/object identities' (RENOV 1999), leads to a collaborative process that speaks about the real world. The self is exposed and reflected through a 'mosaic' reconstruction of the histories and the representations of private lives of intimate others.

The subjective position of the filmmaker subverts from the beginning the aspiration to objectivity, realism, and precision of traditional documentary discourses (NICHOLS 1991). Throughout the process, the filmmaker assumes interchangeable roles of both *insider* and *outsider*. What are the cinematic strategies of reinterpretation, reconstruction, and understanding of the familiar other? How does such a level of access and intimacy affect the construction of the narrative of living with dementia?

For the past ten years, I have been engaged in making a documentary film about the effects of mixed dementia on the everyday lives of my parents. The production strategy on-site went through many changes during this time. There have been situations of shooting a certain event or moments of crisis, weeks of recording the everyday routines, planned interviews but also periods of pauses. I further want to discuss the challenges that emerged during this time. It is an analysis of the choices I made as a filmmaker while shooting on-site when the site is the lives of intimate others. How far can one go with a camera into their personal universe? What are the limits that emerge during the construction of the filmic representation? To answer these questions, I will bring forth my personal experience as a filmmaker working in the private universe of my family and embed it in the wider tableau of filmic representations of mental illness. The analysis will highlight the decision-making process of the filmmaker, the daughter, and the key moments of negotiations between the two personae.

Portrayals of mental illness in film have been a significant source for the reinforcement and even formation of stereotypes. Film is a universal language that has fueled the collective imagination with stories that reflect societal hopes and fears but also offer new meanings and under-

standings about the world around us. Cinema and media tend to emphasize violent, aggressive, bizarre behaviors that serve narrative scopes. Mental challenges often become central to character construction and development. STEVEN HYLER *et al.* (1991) identifies the following common typologies: the homicidal maniac, the rebellious free spirit, the enlightened members of society, the female seductress, the narcissist parasite, and the dehumanized zoo specimens. To this, JANE PIRKIS *et al.* (2006) add the portrayals of irrational, confused characters whose problems of delayed development are often used for comic relief and the hopeless victims incapable of adapting to social norms. Harmful representations pervade the construction of other elements in the universe where mental illness is manifested. Doctors and psychotherapists also tend to fall into archetypal categories: 'the bearded incompetent' with an accent (SCHNEIDER 1987, ORCHOWSKI *et al.* 2006, PIRKIS *et al.* 2006), the one who finds miraculous cures, 'the evil scientist' (SCHNEIDER 1987, ORCHOWSKI *et al.*, 2006, PIRKIS *et al.* 2006), the ones who cross professional boundaries to engage in personal, sometimes sexual relationships with the patient (ORCHOWSKI *et al.* 2006, PIRKIS *et al.* 2006), the rational who in the end is proven wrong by inexplicable cures (ORCHOWSKI *et al.* 2006, PIRKIS *et al.* 2006).

Considerable research has highlighted the impact cinema and media depictions have on audience perception of mental illness. Stereotypes can harvest negative attitudes toward people experiencing such disabilities and reinforce barriers and social distance (SMITH *et al.* 2019, PIRKIS *et al.* 2006). The pervasiveness of such beliefs along with misrepresentation of therapists, doctors, and course of treatment may lead to unrealistic expectations or not seeking help at all. Stigmatization discourages people from engaging in social interactions and increases alienation beyond the degree of their illness (BEACHUM 2010). The appropriation and perpetuation of traditionally harmful visual representation by the media and cinema leaves positive depictions with little effect on the negative social attitudes of the public. However, studies on public reception of documentaries depicting characters diagnosed with schizophrenia (PENN *et al.* 2003, KIMMERLE & CRESS 2013), have shown that they do have a better potential to in-

form the public on the experience and manifestations of mental illness.

Due to documentary films' relation to reality, the public expects to learn about actual people and events (ANDERSON 2003). The dichotomy 'fiction films versus documentaries' has been consistently criticized by film studies scholars (NICHOLS 1991, 2001, GODMILOW & SHAPIRO 1997). There is reality in fiction films and there is fiction in documentaries. The variations between the two stand in their relationship to the truth. Documentaries are constructed representations of 'a particular view of the world' (NICHOLS 2001). They are expected to be not only plausible, as in the case of fiction, but truthful depictions of events. The fictional aspect of reality is produced by the selection of what is captured on camera and the choices the filmmaker makes in the construction of the story. The relationship between the author of the film and the audience is set from the beginning by the convention of the way the film is presented – fiction or documentary. What is essential in our cultural context is the trust in the filmmaker's good intentions.

Content (single shots, characters, and narrative lines even) is edited out of the final version of the film due to constraining of current conventions in terms of form and distribution. The distribu-

tion possibilities of nonfictional video production films are expanding. Filtering the information to mislead the audience is considered unacceptable. However, these types of misrepresentations and omissions are sometimes made due to a lack of understanding of the matter. Attempts to portray trauma behind mental illness can contribute to 'breaking the stigma' (BUTTIGIEG 2020). However, creating a narrative through correlation to explain the cause of a mental illness or emphasizing the decline of personhood for dramatic purposes can lead to the reinforcement of stereotypes that perpetuate fearful, piteous, condescending attitudes towards the people suffering from such a disease.

Important attempts have been made to give voice to the ones who have been diagnosed with mental illnesses, but the outsider perspective of the filmmaker prevails in the way the story is presented. AAGJE SWINNEN (2012) denounces VAN ES's directorial choices in *Verdwaald in het geheugenpaleis* (eng. Lost down memory lane; 2010) – which had the support of Alzheimer Nederland. The narration is constructed in such a way that enhances the constant threat of being moved to a large-scale facility. The film ends with the people discussing euthanasia. Such a perspective reduces people to their illness, disregards other aspects of their identity and reinforces a sense of distance



**Fig. 1** My mother helping my father get dressed.

and otherness. A similar effect was created by the PBS program 'Out of the Shadow' (2008) which was presented as featuring 'the science and treatment of depression with intimate portrayals of families and individuals coping with its wide-ranging effects'. The ninety-minute documentary 'educates the audience about the illness' but the expository style 'creates a separation between subject and viewer' (HUETTER 2019). What cinematic form could undermine the reproduction of 'the symbolic boundaries between 'us' and 'them' (CROSS 2004)?

The construction of visual representations of mental illness raises questions about the power, responsibility, and legitimacy of the ones who engage in such endeavors. The BBC TV series 'Video Diaries' (1990-1996) erodes the boundary between public and private and explores the everyday lives of people suffering from mental illness. Visual engagements of self-representation don't look to explain, but make an 'implicit request for the viewer to recognize the reality of the speaker and to incorporate that reality into his or her view of the world' (AUFDERFEIDE 1997). The failures of conventional cinematic approaches in documentaries that portray mental illness suggest a need for an exploration of more open formats. Documentaries like 'Mum' (Netherlands, 2009) by ADELHEID

ROOSEN and 'Us Against Us' (Romania, 2021) by ANDRA TARARA focus on the present instead of nostalgic recollections of a lost identity. 'By highlighting instead of veiling its means of production, Mum stimulates viewers to imagine people with dementia as other than lost selves' (SWINNEN 2012). The 'performative documentary' (NICHOLS 2001) depicts present interactions between 'mum' and the people close to her. The relationship between Tarara and her father, who was diagnosed with schizophrenia, is portrayed using a split screen technique in which each of them is exposed to the other's camera recording of their conversations. The two films, create a setting in which the 'mum' and the 'father' have an opportunity to reaffirm their personhood through personal interactions with the people around them (HENNELLY *et al.* 2021).

Personal, autobiographical (LANE 2002), first person (LEBOW 2012) documentaries or domestic ethnographies (RENOV 1999) are defined as 'explorations or depictions of the personal lives of the filmmaker during which family members, friends, and others are recorded in sync sound or with the illusion of sync sound' (MACDONALD 2013). These films are a result of a process that starts with a level of intimacy which cannot be achieved in any other filmic engagement (KATZ & KATZ 1988).



**Fig. 3** My mother is talking to the camera about my father's illness while he is listening.

The exploration of the filmmaker's biography is not usually the focus of these films but his/her life story is interconnected with those of the people around (LANE, 2002). These engagements are never solipsistic but always imply a dialogue with 'another' (LEBOW 2012). The prior relationship offers a level of access and intimacy, unachievable in any other filmic engagement (Katz & Katz 1988). But this calls for a particularly enhanced awareness of the responsibility towards the people represented. 'Cultural assumptions that family members should, and will, protect one another lead to more stringent criteria in judging the ethics of film-makers' (*ibidem*) who choose to visually document the lives of intimate others. Even more so when family members are in a vulnerable position such as suffering from a mental illness.

Personal documentaries are a form of representation of the domestic space, of social experiences, some common, others exceptional and traumatic. Having access to how experiences are lived whether its identity, gender, illness, death, etc. it makes people become more than 'social actors who perform ritual obligations with mathematical precision without emotional dimension, or distinguished personalities' (LOIZOS 1992). Because most of the time these are independent productions are not bound by an institutional agenda or profit driven constraints, these documentaries challenge the forms through which otherness is constructed. Documentaries like 'Mum' or 'Us against us' defy public perceptions of mental illness by focusing on the affirmation of the self through the continued engagement in personal and social activities. These pluralities of subjective perspectives come to challenge public discourses on these topics. There are ways in which the histories of anonymous individuals and official history merge and contest each other. Thus, agents of change within social systems can be more easily identified through the lens of individual experiences.

### **From filmmaking to diagnosis and back to filmmaking**

In 2013 I began filming my parents' experience in the first weeks of retirement as part of a research assignment during my MA. Like many others in post-socialist Romania, after the factory where

they spent most of their lives closed down, they faced over a decade of struggling to make ends meet by slaloming between underpaid jobs on the black labor market and unemployment. What I was hoping for was to observe and record the changes that occurred in their everyday lives as a consequence of their new status. My assumption was wrong, as their routines did not alter overnight. However, I did notice something different in my father's behavior. His daily activities were the same, as he had been unemployed for two years. However, some difficulties in the way he communicated and interacted with me and my mother caught my attention.

During the shootings, I've had several failed attempts to interview my father. It was difficult for him to give me the coherent answers I was looking for. He had never been much of a storyteller. I always thought of him as an introvert with the most inspired effortless punchlines. He is ethnic Hungarian and he always had some struggles speaking Romanian, as it is his second language. He rarely engaged in long explanations or depictions because when he did, Hungarian and Romanian grammar and lexicon collided into confusing stories. It was not unusual for him would look for the right words, and find unusual substitutes or long expressions for common words in Romanian. I never learned Hungarian (being a Hungarian was not something to be proud of) so I considered any mistakes in communication to be due to his mother tongue. This, along with 'getting older' and maybe camera shyness became a viable explanation for a while. My mind changed during the editing process. Revisiting over and over the shots of my father, away from other disturbances and stimuli, I became more aware of the scale of his speaking difficulties. The long pauses, stutters, half-articulated words, and unfinished sentences made it very hard to edit and reconstruct coherent discourses. His confused or distracted facial expressions were not something I was familiar with. He may have been an introvert but he was very focused on the conversations and his interventions were always right to the point. I insisted he'd see a psychiatrist. He was soon diagnosed with mixed dementia.

A documentary approach that relies on conventional techniques has seemingly failed in capturing the voice and experience of the person in front



of the camera when that person doesn't communicate according to social standards. It took a few years until I decided to record my father's experience of living with this new illness. As a filmmaker, I felt it was an important story to which many people could relate. As a daughter, the camera became a pretext for being present. My initial intention was to follow the everyday struggles of someone who has faced this diagnosis and how this degenerative disease is affecting this person I knew all my life. It became a process of (re)discovering a familiar context and the way is being shaped by the new reality. It also meant a search for a cinematic approach to communicate a story about someone who is losing their ability to communicate.

### **(Re)discovering and reframing familiarity**

As mixed dementia progresses social relationships are affected by the difficulty of communicating verbally. My father was always an introverted man with a social life structured by the relationships that his job ensured. The mother, on the other hand, has an extroverted personality, which tends to overwhelm those around her and also the action within the frame of the camera. Due to the degeneration of my father's physical condition, the relationship between them became that of caretaker-cared for. Until the moment of the diagnosis, this type of dynamic was somewhat established due to her more efficient adaptation to the labor market, something that greatly imbalanced the power relations within the family during the deindustrialization period. But if up to that moment, this was an effect of a combination of social causes, the labor market and the political situation, since then, dementia seems to have defined irreversibly their roles.

The dominant attitude of my mother required finding strategies to explore my father's quiet character. The times when the two are not together are very rare. Although the communication difficulties have amplified his isolation from conversations in real life, I tried to use the camera to reframe his seeming dynamic with the people around him by focusing on my father's body language. Recording close-ups of my father while my mother was talking, allowed me to observe and capture his reactions to her manifestations.

The ironic or disapproving looks, the frowning, smiling are still very present in his face. These are indications of his presence, awareness, and perceptions of the things happening around him and contribute to a depiction beyond the apparent absent person. Another strategy to create more space for him to express himself in front of the camera was by using the camera as a catalyst and inviting him to participate in conversations up to the point of interrupting my mother while she was talking.

Familiarity with the domestic space and prior knowledge about the dynamics of the two is an advantage in anticipating actions and reactions to be caught on camera. My parents have lived in the same space since I was born. I knew where they spent most of their time, where they carried out their activities, their body language, and their reactions. I knew the bed my father would sit in after eating and that he wouldn't last very long in the same position. I knew the cat would come next to him because he is warm and always sleeps in the duvet. I knew that my mother is anxious and that when she talked on the phone she walked around the house and raise her voice. I knew how the light came through the windows and what the darkest corners were. When going shopping, I knew in which order my father would enter the stores. This type of familiarity allows a certain control over the possibility of recording spontaneous moments on camera. Small moments like entering an empty room and ignoring the camera, sitting in an empty chair in the middle of the shot, reacting behind another's back or even falling asleep informs the viewer about the level of trust and intimacy that exists between the filmmaker and characters. When filming onsite people I don't have a prior relationship with, there is a period of exploration and learning about the other's routines. The process of observations becomes mutual. While I come as the observer, I am also observed by the people in front of the camera. Trust must be built. In the first stages of interaction, I constantly inform them of the process and disclose information about my intentions. Besides the story I follow, I also often give explanations about why I'm sitting in a certain place or why I'm interested in filming certain activities that may seem banal. The distance between the filmmaker and the ones in front of the camera often finds its way onto the

screen. Nevertheless, even in the most familiar space, when relations are being mediated by the camera a distance and unfamiliarity intervenes. The filmmaker swings back and forth between the role of the *outsider* and *insider*.

### Stances of the camera

Distance and closeness coexisted. My insider position became subverted by the presence of the camera and by taking the role of the filmmaker. The outsider's interest also brought us closer. My father's illness was something I was only beginning to understand. After his diagnosis, I distanced myself from them for a while. I disapproved of their life choices and lack of care for themselves. I believe it was the main reason for the deterioration both of their health. The camera was a pretext to reassess my attitude. My initial shootings had a voyeuristic perspective and the camera served the outsider's curious gaze over unfamiliar behavior. I saw my father as a victim and used searched for a confirmation of that narrative through the lenses. Constantly being present not only physically but also paying attention to what was happening on the small camera screen, reconfigured my perceptions. Up to this point, during our usual encounters, I would many times get distracted or to easily

get into conflicts. Our meetings used to be chatty and noisy. Now both my father and I were quieter than our 'usual selves'. I sat staring into the camera without speaking even for hours. He would sometimes try to say something, maybe respond to my mother, or ask me a question, but many times he would give up, after not finding his words. The function of the space changed for each of us. The kitchen had only been the place to prepare food, to talk, to watch TV. They both began to adapt their movements based on where I placed my camera and moved objects to have them more within their reach. As time passed, they also adapted the room according to my father's limited movements. They bought a more comfortable chair where my father would spend most of his time. My camera also became more fixed, just across the table from him. I began to (re)discover the domestic space and those who inhabit it. This way of observing them created the context to learn about new behaviors but also some I didn't know existed.

Video recordings allow observing people beyond direct communication, through moments of silence and small gestures. Mom's outgoing behavior attracts the attention of the people she is in the room with. By pointing cameras at my father while she was talking or doing some activity, it allowed me to observe and capture his



**Fig. 9.** Me and my father talking for the first time about his illness.

reactions to her manifestations. His lack of engagement in conversations turned out to be an appearance I chose to believe. I discovered reactions like looking away when there is something he doesn't agree with, the frowning, the sigh, the pursing of the lips, etc. I also witnessed her critical and disapproving attitude reflected on her face. The camera created the opportunity to observe these subtle aspects of their relationship but also shielded me from conflicts. It became a barrier that blocked the instinct to intervene in discussions or state my mind about things I did not agree. Relating the position of the filmmaker defused the tensions.

The professional stance that disciplined me to focus on the process of filmmaking revealed my mother's actions as a caregiver and her coping mechanism. While at home, her time was structured by my father's routines that she had to assist and house chores. Filming her was predictable. When I decided to follow them on a trip planning a station point or angle of the camera had to be reconsidered many times. No longer having the physical constraint of domestic space, it became almost impossible to keep her within the limits of the frame. After placing my father in a chair, sometimes she would prepare to relax in the sun, but shortly after sitting down, she would give up and look for something else to do and 'disappear from the shot'. Checking the time code of the video camera, I found that I was able to capture frames of a maximum of one maybe two minutes of her engaged in the same activity.

### **Reconstructing the past through interviews**

Interviews have been a means through which I wanted to preserve my father's memories. They were a way of reconstructing the life story we no longer had that can't be seen. To highlight the changes that occurred after the diagnosis I believed that the past should be remembered and narrated. On the one hand, it served my initial gaze that looked to focus on what is lost and present it within a nostalgic framing. On the other hand, as a daughter, I wanted to have records of his life story, of our life stories. It became a process of preserving memory while memories fade.

The interplay between insider and outsider on the one hand brought forth information the

daughter didn't know on the other, the daughter helped reconstruct lost moments of the past. The access to this intimate situation and the openness of the two subjects, characters, was a consequence of the personal relationship between me and them. The daughter is the one who knew the mechanisms by which the two would agree to be questioned and filmed in the domestic space. The questions I raised were based on my own lived experience with them. The presence of the camera was a form of legitimizing questions I presumably knew the answer to or some that had never been asked. It brought a formalized aspect to the discussion framework. As a daughter, I had access to prior information about the past and also their trust to share it. But the camera introduced an outsider, the filmmaker, as the dialogue partner. It brought out a different attitude and a new way of relating to one another. Our usual interactions unfolded according to certain patterns and the communication was infused by emotional reactions. In this new context, my professional motivations blocked my automatic responses. A silent person appeared in front of them, not responding with laughter or anger. They repositioned themselves and unfamiliar attitudes and behaviors were revealed. I presented myself as a filmmaker and they responded as pensioners, one diagnosed with mental illness, as caregivers, not as parents. My mother's attitude shifted during the shootings from jovial and humorous to confessions about the hardship of her experience as a caregiver. My father didn't evade my questions, or dismiss them, as he did in our past conversations. Although it was the first time he made an effort to recollect with detail and emotional engagement, his ability to put them into words undermined our process.

The degree of interpenetration of my life history and theirs was so high that the reconstruction of the past was a highly collaborative process. Through the 'how about the time when...' approach, lost fragments of the past were elicited and recovered by core memories in my own biography. In the interviews with both of them, the two were 'correcting' their stories and narratives about the past or adding information to each other's 'pieces of memory'. The whole process was a negotiated reconstruction and re-assembly of memories in the form of a puzzle.



### Stepping in front of the camera

A turning point was the moment I decided to step in front of the camera and reveal upfront the dynamics of our relationship. As time passed and the illness progressed, I became more aware that remaining behind the camera would not be a truthful depiction of my father's experience. The most significant aspects of his life are the relationship with my mother, me, and my brother. His personhood and his personality are affirmed through his engagement with each of us. I looked for an opportunity when my mother was away. I wanted to create a context where he would have more space for him to express himself. I left the camera on a tripod and sat next to him in a two-character frame. The camera became a catalyst for our first meaningful conversation. I built the courage to ask questions that I had asked only in my mind. I was surprised by my father's willingness to talk about topics that have been taboo in our family like his awareness of this condition and his dependence on my mother.

It was the first time in my life that I had a serious talk with my father. We've had conversations before, just the two of us, but we've never approached personal topics. The filmmaker also wanted to reveal more of this silent character. I was surprised by the willingness of my father to answer questions that were taboo in family discussions. Moreover, I discovered a greater dose of coherence in expression than was in my perception at the time. In this discussion, I heard my father say that he loves my mother, but also that he is aware of his disease and that he fears that she will not love him anymore because of this disease that makes him stubborn.

In the editing process, I had a difficult time looking at myself as a character. I considered the option of discarding the video and just preserving the sound. The lack of comfort I felt was easily visible on screen. The first time I reviewed the footage, I regretted the decision to position myself in front of the camera. It was very difficult for me to look at myself and I thought that even for a stranger it would not be a comfortable experience and would distract from the content of the father's answers. It took a while to reconsider this perspective.

The initial decision was not to position myself in front of the camera because I did not want the focus to be on my relationship with them, but rather on the changes that occurred in their lives. I came to realize it was a blind spot. I was part of the story from the beginning. When remaining behind the camera the perspective of the filmmaker is seen through the cinematic language: in the framing, the camera movements, focus, sound, *mise-en-scène*, the montage, and the structure of the story. By penetrating the line that separates inside and outside the camera frame and exposing myself along with my parents provides the opportunity to witness my reactions as a daughter to what the two are saying and doing. This moment captures very well the 'daughter's' fear of having this dialogue with the father and the filmmaker's sense of risk of exposing herself in front of the camera. It also reveals both character's vulnerable positions and fear of having this dialogue.

### Conclusions

When I decided to make a documentary film it was because I wanted to make sense and create a narrative of what it means to live with dementia. My knowledge about this illness and what I imagined I am going to witness and record on camera were shaped by the films and media portrayals I was exposed to until then. The initial script was the story of a vulnerable person, a victim, whose identity will fade away by the end of the film. As the shootings progressed, the story became about a search for understanding and connection. In the beginning I was motivated by the idea that the film will be a way through which my father, whose relations became mediated by my mother, will be engaged with the outside world. I came to learn that what he needed was to be seen and acknowledged by the ones in his proximity. The process of filmmaking has recorded and also reshaped our relationships. The camera captured the transformations of my father's interactions with my mother and me after his diagnosis. Nevertheless, process of making a film became a part of our life stories and altered them.

The interchangeable roles of insider and outsider allowed taking distance and understanding from different perspective but also getting closer by rediscovering each other in new ways. Dis-

curring traumatic experiences was possible due to a rupture of our conventional ways of relating. Exposing their fears and insecurities, questioning one's identity was not part of the routine of our domestic intimacy. A new kind of framework was created in which I positioned myself as an outsider, as a filmmaker. The placement of the camera between us served as a form of legitimizing the presence of 'the other'. In this new setting my parents repositioned themselves as dialogue partners with a much more sober attitude. Throughout this process the camera has become an ally that helped me as a daughter formulate and questions I haven't thought of before or haven't had the courage address. However, the access to this experience was given by the insider, the daughter. They trusted me and I knew the mechanisms to inform them of my intentions and reassure them they will be protected.

For the daughter making this film is a form of preserving my father's memory as it fades away. As a filmmaker I hoped to invite consideration of the terms on which people that experience dementia are represented on screen and given a public voice. I decided to step in front of the camera and undermine the privileged role of an observer by also becoming observed and submitting to the risks of the public's gaze. My subjective position undermines the voyeuristic pleasure of seeing from a distance the experience of the other. Hence, the self is exposed and reflected through a 'mosaic' reconstruction of the experiences and the representations of the private lives of my parents. The story will not explain the challenges of living with dementia it will depict my experience of learning about how my father experiences this illness. Will the public acknowledge my experience? Has such a form of public representation had any potential to ameliorate perceptions of people living with dementia?

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### Notes

- 1 The role of visual culture has grown considerably since the emergence of the problem of representation. Over time, the discussion framework has been nuanced by the proliferation of representations of one's own culture, or of those with whom the one undertaking the endeavor "shares the same social, cultural and linguistic background" (LIAMPUTTONG 2010). With the emergence of new modes and possibilities of practice and reproduction, new questions have emerged that interrogate the problem of representation: Who should and who are those who produce them? Are they inside or outside? What are the forms through which these representations are produced (collaborative, reflexive, problematizing cultural stereotypes)? What kind of topics do they address and how are they (re)presented?
- 2 Film website: <https://www.pbs.org/wgbh/takeonestep/depression/about.html> [05.10.2024].
- 3 Other types of defining personal audio-visual cinematic engagements: essay (RASCAROLI 2009); vernacular (DOVEY 2000), family films (MORAN 2000), performative (BRUZZI 2000) – as discussed in *The Cinema of Me: The Self and Subjectivity in First Person Cinema* (ed. LEBOW 2012) and reflexive or self-reflexive (RUBY 1988, NICHOLS 1991, MACDOUGALL 1998).

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