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18. MYFUTURES: IMAGINING SPECULATIVE CARE AND SUPPORT FUTURES IN THE NETHERLANDS

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Abstract: In many Western societies, decisions about leaving home and spending your last years in a care home are often taken suddenly. Immediate health issues force family, friends and neighbours who offer informal support to ask for immediate formal support. Such urgent situations do not lead to the best solutions.

MyFutures is a 2-year academic-public-private project to create services and tools that take the future thinking and making skills of designers and put them in the hands of the people taking future care and support decisions.

We use speculative design and film to think beyond the immediate, using imaginable future care and support options in the Netherlands as our material. This will allow people who need care and their (in)formal caregivers to get familiar with many more options and the power of creativity as sources for bespoke future solutions. Our approach states that the future is plural, and should not be predicted but imagined in many ways to be prepared for what may come. MyFutures translates this designer-ly way of thinking and working to the daily reality of people in need of care, and their caregivers.

18.1 > INTRODUCTION: THE MYFUTURES INTERVENTION

In recent decades, in North-Western European societies, the state used to guarantee full support to older people and those with chronic diseases concerning the care that was needed, including where and how to live - in an old age home for instance. However, in current North-Western European societies the state no longer makes these choices for you, nor does it always provide standard services including housing. Nowadays, older people or those with chronic diseases need to decide on where and how to live in the future themselves, including how formal and informal support can be organised. Family and friends often play an important role at this moment in life.

The MyFutures project was set up to investigate and intervene in these situations. It is set up as a Research-Through- Design project (Stappers and Giaccardi 2017) aiming to develop tools and support for people to design their own futures. Led by two academic institutions, Technical University Delft and Design Academy Eindhoven, the project brings together more than ten partners including the cities of Eindhoven, Rotterdam and The Hague, two Health Insurance companies, care organisations and four creative agencies. The key premise of the project is that designers have tools and skills that allow them to explore multiple ideas, solutions and futures, as an integral part of doing design, see e.g. Dorst (2015), and these skills may be valuable to people in general who need to take decisions on their future too. We included speculative design and design fiction (Dunne and Raby 2013) in the project to add techniques that help to imagine further ahead than most people do in everyday life. The aim is to come to empower individuals to more broadly explore their possible futures, think about them, and act toward them.

The MyFutures project consists of a combination of research, education and case studies. In the first half of the year, we have built the scaffolds of the framework on literature, interviews with experts on the topic and everyday people and workshops with our partners. As a result, specific moments in people's lives were identified where people seem to have a need to discuss their thoughts, feelings, expectations with others. We learned that 'in discussion with others' is an opportunity where it is rather natural for people to open up and reflect on people's own thoughts, feelings and wishes. Three of these everyday moments were selected to investigate in further detail through case studies. The first case zooms in on the first time when making a care plan with professionals is needed. The second case zooms in on the moments of family meetings. The third case zooms in on socialising moments. This last case is where we are using film in our design research. One finding in our research was that social needs are a dominant factor in thinking about and organising personal futures. People can feel lonelier as they grow older, and they can feel it is no longer worthwhile to invest in new relationships because time has become short. How can we stretch this thinking towards more open futures?

We use speculative design and film to support this stretching and think beyond the immediate, using imaginable future care and support options as our material, from robots and exoskeletons, to growing new organs and living well beyond 100 years. How would a future with these kinds of options look like? Our approach states that the future is plural, and should not be predicted but imagined in many ways to be prepared for what may come. MyFutures builds on ways that designers use to think about and work with futures, and aims to eventually translate these into

tools and activities that older people and their caregivers can use to design their own futures from the perspective of new possibilities, rather than shrinking options. Science is a good source for inspiration if one wants to expands ones options, because science has expanded how we can live and what we can do over many past decades already.

18.2 > SCIENCE FICTION: POSSIBLE FUTURES IN THE NOW

How can one bring the science of today that is the basis for what we can do in our futures, to people already now? Science fiction film has since its start (arguably the film 'A Trip to the Moon' (Le voyage dans la lune) by Georges Méliès, 1902) done exactly that, by fuelling the imagination of large audiences. The genre is a great example of how a society as a whole and many people in it can dream about possible futures, both good and bad. It is important here that two seemingly opposites (science and fiction) are connected into a coherent story that is perhaps not likely but can be seen as plausible, at least for the duration of the film. Much science fiction works on the principle of 'suspension of disbelief,' a call upon its audiences that is also used by designers to imagine futures or alternatives to the current situation. A relevant example in this context is the film 'Uninvited Guests' by design research studio Superflux (2015) where the science of the Quantified Self and Internet of Things, already introduced in society today, is imagined to progress towards monitoring systems that keep an eye on the health of older people, indicating the healthiest lifestyles to them personally. In the film, an older man living by himself is using several monitoring systems like a fork that measures the healthiness of the food he eats, a cane that checks how much he walks and a bed that monitors when he goes to sleep and wakes up. He is not interested in the numbers these provide, but some of his family and carers are, and they keep sending him messages that tell him what to do more, or less, and when to go to bed. He is clearly not interested and seems to rather be left alone. Soon enough he starts to find ways to be left alone by fooling the sensors. He asks the lad from next door to take the walking stick with him for a while, in exchange of a can of beer, for instance, and puts piles of books on his bed when his supposed bedtime arrives. He ignores the compliments the system and his family and carers send in return. They are less frequent and less irritating than the previous reminders to do more and better. The film helps to understand what monitoring and mentoring services may be possible soon, and encourages debate around what is desirable. At the same time the film suggests that people will use Quantified Self and Internet of Things technologies creatively in unanticipated and unintended ways. This encourages viewers to think about how they would like to use these systems to their own benefits, and avoid their negative effects.

18.3 > ETHNO-FICTION: DESIGN RESEARCH AND FILMMAKING

Ethno-fiction is much less known than science fiction but also relevant to the work we do. Ethnography is very widely used in design research, but not in combination with fiction. In the late 1950s, Ethnographer Jean Rouch developed the idea of what was later called "ethno-fiction" (Stoller, 1992, p. 143) to emphasise that in ethnography fiction is as important as facts. According to Rouch, "[t]he world in which we live is a twilight zone, an area of light and dark, truth and falsehood, reality and fiction" (Grimshaw, 2001, p. 117). Working in West-Africa with the Songhay and the Dogon (both oral cultures), but also in Paris, he focused on the mix of stories and facts in everyday life, and he learned that fiction and stories teach us things about the human condition

that no rational cultural analysis based on distant observation can achieve. To Rouch, this does not mean that factual filmmaking should be left completely in favour of fiction. Rather, he argues, we should use both; fiction techniques like storytelling, improvising, performing and acting must be incorporated in the working methods of ethnographers and documentary filmmakers. He explores these ideas extensively in his own films, for instance The Human Pyramid (La pyramide humaine, 1959) in which he sets up a fictional story about relationships between black and white young people in colonial Africa, exploring teenage love, jealousy and racism at the same time. At the start of the film he gets a group of students in Ivory Coast together to make a film about how relationships between black and white young people can exist without racism. He proposes to them to use ethno-fiction and invites them all to contribute to the scenario which they will write during the making of the film. The outcome is not preset. Rouch warns them that someone will have to play the racist and others victims of racism, and that they have to stick to this role, like villains in other films do. "So everything is staged?" asks one of the students. "What do you mean by staged?" Rouch replies, "I create an experience." For Rouch, the camera does not capture reality, it creates reality – or ciné-reality as he calls it (Stoller 1992, p. 193). He knew his protagonists would change their normal behaviour in front of the camera. But that does not destroy what he wants to film. It creates what he wants to film: a dialogue between him as an observer, the protagonists and even the imagined viewer of the film because both he and his protagonists think about how the story can be told best.

18.4 > ETHNO-SCIENCE FICTION: FILMING THE ELDERLY

Taking inspiration from both science fiction and ethno-fiction, we create films in the MyFutures project that combine both approaches and thus might be called ethno-science fiction films. We combine two different sources of film material. On the one hand, we use interviews with scientists about their work, exploring technologies, the human mind and body, as well as social and cultural aspects of being older. These were originally recorded for the TV-series 'The Mind of the Universe' by VPRO public television in the Netherlands, who made the raw footage of the entire series available as an Open Source Science TV project (VPRO 2017), for the public to edit their own films, making us of the Creative Commons Attribution-ShareAlike 4.0 International license. Secondly, we film with older people scenes from their daily lives that somehow connect to some of the stories the scientists tell. In editing, we then combine the two to create ethno-science fiction stories that allow for multiple interpretations. One example is called Pascale Fung and Det, a two-minute film in which scientist Pascale Fung explains how robots will enter into our lives and that we will have to collaborate with them: It is necessary for the robots to interpret what we mean, and this obviously goes way beyond taking what we say literally. She also mentions exoskeletons as a particular type of robot that will help us walk. While Pascale Fung tells her story, at times we see Det, a woman in her eighties who walks outside her home in her garden with a rollator walker. She ends at a garden chair that she puts in the right position before lounging in the sun. Then we cut back to see Pascale Fung again who ends with a statement about how robots will not only enhance our physical abilities but also our mental abilities, allowing us to not only do more but also know more and understand more. These two minutes of film give rise to a wide range of options and possibilities (service robots, exoskeletons, knowing more instead of forgetting when you get older), that on the one hand sound rather futuristic (collaborate with

robots instead of robots as slaves), but on the other are directly connected to what exists now in older people's lives (equipment that helps people to walk, the internet that gives access to ever more knowledge).

Fig 18.1: Det in the MyFutures film. Personal photograph by authors. 2017.

We designed this film with three characteristics of ethno-science fiction films in mind. Firstly, the film needs to be grounded in the reality of older people in some way, to provide anchor points for viewers to connect the film to their own lives. We see an opportunity here to collaborate with people, just like Jean Rouch does with his ethno-fiction when he creates the story with his protagonists. The older people we involve in our design research are invited to decide with us what parts of their lives can be connected to the stories of the scientists. Secondly, we use film as a language that everyone understands easily. The interview with an expert, the observation of an action, and the cutaway technique that creates a connection between the two, are all part of a film language that people understand without effort. It is a simple way to create speculative connections that are accessible to everyone. It encourages us to dream about possible futures, both good and bad, just like science fiction does. Thirdly, ethnoscience fiction is aimed at creating spaces for speculation, where our thinking about the future can be stretched and conversations with people directly involved can be had. The

Fig 18.2: Pascale Fung in the MyFutures film. Personal photograph by authors. 2017.

films must provoke personal conversations about possible futures. Here, we see connections with the use of film in participatory design, and can build on these to intervene in the conversations that already take place between professionals, formal and informal carers, and the people needing the care.

18.5 > FUTURE WORK: INSIGHTS AND APPROACHES TO FUTURES

Current conversations between care professionals and people needing care and their informal carers in the Netherlands consider the future life of an older person in need of care, to assess how different support options may result in different ways of living and consequently how his or her future life may look like. However, in reality the focus is on finding a solution for problems that exist now. The future, let alone multiple futures, are rarely considered. Besides the need to solve an immediate problem, the argument used is also that "as an old person you have no future", as an 89-year old participant in our initial round of interviews told us. We also were repeatedly told that "it does not make any sense to think about the future because you don't know what will happen anyway." And: "You could fall ill anytime and then all your plans are suddenly useless." Older people seem to live a permanent lottery. They take life as it comes. This insight made us reconsider the way we approach futures in our project. We have learned from people like Liz Sanders (2017) and design research studios like Summn

(2017) that the futures should be played rather than planned. Scenario planning may seem attractive but it defeats the purpose if you want to choose for a particular scenario that you then want to work towards. Instead, uncertainty and coincidence should be taken much more seriously and your possible futures are about how you well you are prepared to respond to these once they happen. Often these unplanned events are expected to be negative, when illness strikes for instance, but they can be positive too when people near to you get suddenly more time to spend with you for instance, or when some money is inherited. Where Liz Sanders has explored this approach to futures using physical space, objects and interaction, we are exploring how we can play the futures using film. Liz Sanders proposes that "in addition to planning the future, we should be playing in the future. The playing would involve enacting and pretending and using the body to explore future scenarios: not just planning. That would give a lot more ways for people to dream about the future." (Sanders, 2017. p. 32) With ethno-science fiction films we aim to contribute to this effort and take it into new areas and directions, to allow more people to play with their futures. Film is a great medium for this, because as McLuhan already pointed out it is a highly participatory media, where empathic engagement has to be invested to make sense of the material (McLuhan 1964). The participation that film as a medium makes possible is very different from engaging with written or diagrammatic representations such as scientific papers, formatted by a long and delicate process of professionalisation (Latour 1990). Participation through filmmaking is a way of manipulating material that can handle the 'flow' of real life interactions without the detour of putting it in writing (Buur et al. 2000, p. 340-341). Adding the fictional element makes the ethno-science fiction films speculative and playful because it explores situations that might exist. This is a basic design skill and attitude that we aim to bring to everyone at moments they need to consider their futures.

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