
VISUALISING RAPID LIFE TRANSITIONS: ETHNOGRAPHIC DOCUMENTARY FILMMAKING THROUGH SMARTPHONE- BASED COLLABORATIVE RESEARCH

Kana Ohashi, *Department of Communication Studies, Tokyo Keizai University, Japan*
Daijiro Mizuno, *Kyoto Design Lab, Kyoto Institute of Technology, Japan*

ABSTRACT

Many Japanese individuals fall victim to the disease of cancer, making it the most common cause of death in Japan. The second author Mizuno's wife, Mie was diagnosed with stomach cancer in May 2017, just before the delivery of their first child. She passed away three months after their son's first birthday. Mie's loss made Mizuno a widower and a single father. Up until then, the life transitions of family caregivers who became young widowers during the infant-care period were scarcely documented in academic studies in Japan. Mizuno had started to record himself and his family's life using his smartphone camera almost every day ever since he was informed of Mie's cancer. From June 2018, he started a collaborative research with the first author Ohashi to understand and express the rapid and unpredictable changes of his family's lifeworld. The authors began to share diaries and visual images generated with his smartphone and arranged to have weekly online interview sessions to collaboratively reflect on the files. Eventually, the authors made an ethnographic documentary film to express the rapid life transitions experienced by Mizuno. In this paper, the process of how the authors applied multiple methodologies to develop the research project will be reflected and described. Secondly, the characteristics of the visual images recorded on Mizuno's smartphone during the project will be analysed. Thirdly, the findings and implications of visualising the experience of life transitions as a family caregiver will be elaborated. Lastly, the authors will discuss how we can understand and visualise the life transitions experienced by family caregivers, given that smartphones are a part of everyday life for many people nowadays.

KEYWORDS

Life transitions, family caregiver, design research, visual ethnography, mobile methods, smartphone, documentary filmmaking.

BIO

Kana Ohashi (Ph.D. in Media and Governance) is a visual ethnographer and currently working as a full-time lecturer at the Department of Communication Studies, Tokyo Keizai University, Japan. Her research interests include everyday mobilities practices, transnational communication, and visual ethnographic methodologies.

Daijiro Mizuno (MA/PhD RCA) is a design researcher and currently working as a Professor at KYOTO Design Lab in Kyoto Institute of Technology, Japan. His research interests include design research and interdisciplinary design.

ohashi@tku.ac.jp

daijirom@hotmail.com

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Research background

1) Family caregivers of cancer patients and their life transitions

Note by Mizuno (8 August 2018)

Mie was older than me. I didn't consider having children because she had already passed the ideal childbearing age when we met. At that time, I often travelled overseas for business and to local towns of the country and worked until midnight. I would have to change my lifestyle if I had a child, but I didn't dare to think about having one considering her age. But eventually, Mie told me that she wanted a child, just like ordinary families. She was 42 then. She had experienced a miscarriage before. Moreover, there are a lot of schedule restrictions on infertility treatment, and it is expensive. We needed to decide when to stop trying. The communication between Mie and myself regarding the treatment was particularly challenging for me when no results were gained.

Despite the situation, her urge to bear and to raise a child was very strong. At any cost, Mie longed for the happiness gained from having a family (she did not enjoy working). Child-raising alone—and not through accomplishments from work—could confirm her identity. I guess she arrived at the conclusion that having a family—a child—was her aim in life after she was successful in living at her own pace.

Finally, in Autumn 2016, an artificial insemination was successful, and our baby grew remarkably inside her as she went on to overcome her high-risk pregnancy. In April 2017, she was ready for delivery. At that time, she was busy attending child-rearing preparation classes, doing exercises and yoga, going to obstetrics and gynaecology hospital appointments. Her due date was expected to be at the end of June or beginning of July.

However, Mie gradually developed what seemed like late morning sickness. She lost all her appetite. Though she had various prescriptions from her obstetrician, she could barely eat. Something was wrong. On 19th May, she had a periodic medical check-up.

Immediately, the obstetrician gave us an introductory letter to consult a doctor at a general hospital. We rushed there anxiously. The doctor admitted her into the hospital at once. A week later, a detailed examination revealed that a stomach cancer had caused the condition. The cancer had narrowed the exit of her stomach and had blocked any food consumed from reaching the bowels. As she was nine months pregnant, we decided to opt for a caesarean, forgoing natural birth so that she could begin and concentrate on cancer treatment immediately. We cancelled all our plans to give birth at a maternity clinic and to have luxurious festival foods in celebration of the arrival of our child. Everything was going against our own decisions.

A pregnancy-associated stomach cancer. A rare case, which is also associated with poor prognosis. It was scirrhus stomach cancer, a type that worsens the prognosis. Even though I am not an expert in this field, I discovered this information from reading medical articles, as I am a researcher. Disappointed. Wiped out. With the imminent delivery, Mie wished from the bottom of her heart, that I would not be unhappy.

In Japan, approximately 62% of men and 47% of women get diagnosed with cancer in their lifetime (National Cancer Center Japan 2019), and one in 3.6 people succumb to death as a result (Ministry of Health, Labour and Welfare, Japan 2018). This means that many Japanese people not only experience their own battles against cancer, but many have to care for their family members who are diagnosed with cancer. In recent years, an increasing number of young workers and those in their prime years suffer from cancer during the period of child-raising. Accordingly, many young people become family caregivers. The family caregivers are expected to take responsibilities for decision-making, providing substantial caregiving, meeting the financial and social costs, maintaining stability, and adapting to change (Onishi 2009). Onishi (2009) points out that family caregivers should be considered as 'second-order patients', because they are under intense mental, physical, and social stress from the moment their family member is suspected of having cancer. However, studies also show that very few family caregivers receive necessary social support as 'second-order patients' (Matsushita et al. 2010).

As described in the note above, the second author, Mizuno's wife Mie was diagnosed with stomach cancer in May 2017, just before the delivery of their child that the couple had been eagerly awaiting. Mie began to live with medical treatment immediately after giving birth. Nevertheless, she passed away three months after her son's first birthday. During that period, Mizuno had to manage to balance work, childcare, and care for Mie. Mie's loss made Mizuno a widower and a single father. Mizuno's role in his family transitioned, and environmental transition also occurred rapidly. This kind of life transitions experienced by young widowers during the child's infant-care period are scarcely documented and investigated as academic studies in Japan (Kondo and Sato 2007; Shirakawa 2015).

According to the 2016 Nationwide Survey on Single Parent Households, there are 1.23 million

mother-child(ren) families and 187,000 father-child(ren) families in Japan (Ministry of Health, Labour and Welfare, Japan 2017). The loss of the partner was the main cause of motherlessness for 19% of father-child(ren) families. In Japan, previous studies have largely focused on issues regarding mother-child(ren) families, as most single parent families were predominantly mother-child(ren) families, and many were confronted with serious economic difficulties due to the delay in women's participation in society (Lee 2019). The concepts of 'division of labour by gender' and 'maternity myth' are still deeply rooted in Japanese society, and this is considered to be another reason for the focus on supporting mother-child(ren) families. Shirakawa (2015) found that young male parents or those in their prime of life caring alone for underage child(ren) are more likely to lack a confidant to consult with and be isolated from childcare information and role models. Given this background, it is crucial to understand the experiences of single male parents who cared for the partner through their last days and consequently, were forced to raise their child(ren) single-handedly.

2) Visualising the life transitions experienced by a family caregiver of a cancer patient

According to Pardo and Morcate (2016), the visual representation of illness, death and grief has been changing through the years and it relies heavily on the cultural context. There have been many indications that death and death-related topics have been tabooed, covered up, isolated, excluded, denied, and/or suppressed in modern Japanese society (Sawai 2002). As mentioned previously, there has been a problem of family caregivers of cancer patients not receiving the necessary social support they need in Japan. One of the reasons for this problem is the hesitance of family caregivers to express their needs and feelings (Muta 2018). There are cultural norms that may underlie this hesitancy and resistance to expressing emotions related to illness, death, and grief.

However, in the age of smartphones and social media, expressing and sharing the experiences by patients and family caregivers themselves is becoming less unusual. For example, Ameba Blog, one of the largest blogging services in Japan, has more than 150 official tabs or genres for users to specify what their blogs are about, and categories like 'caregiving diary' and 'hospitalisation and disease fighting' are on the list. Over 40,000 users have chosen these two categories for their blogs as of August 2021 (CyberAgent, Inc. 2021). This is not a big number when you consider that Ameba Blog has 67 million users in total. Nevertheless, the publicist of Ameba Blog points out that the popular blogs tend to be the ones that write about their experiences related to love, care of the family, illness, etc., which they do not often talk about with others in person (CyberAgent, Inc. 2019). People's practices of expressing and sharing their experiences as family caregivers are being driven by smartphones and social media. Pardo and Morcate (2016) indicate that people are willing to share their stories of illness, grief and death using social media, in the hope of meeting others, increasing social understanding, and making a difference.

The authors of this paper made an ethnographic documentary film titled 'Transition' together in 2019. The film aims to understand and visualise the life transitions experienced by Mizuno, who cared for his wife until her death, while having to work and raise their new-born son in parallel. Mizuno recorded himself and his family's life using his smartphone camera almost every day ever since he was informed of his wife's disease in May 2017. In June 2018, Mizuno decided to start a research project with the first author Ohashi to understand and express the rapid and unpredictable changes occurring in his family's life. The authors began to share diaries and visual images generated with Mizuno's smartphone on Google Drive and arranged to have weekly online interview sessions to collaboratively reflect on these files. A total number of 1,921 photos and videos were taken during this period. Eventually, the authors decided to make an ethnographic documentary film to express the rapid life transitions experienced by Mizuno as a family caregiver.

Research Aims

In this paper, firstly, the process of how the authors applied multiple methodologies to develop the research project will be reflected and described. This project was not clearly designed or planned in advance. In the process of confronting the events that had happened to Mizuno and his family, Mizuno and Ohashi sought a way to make the experience the focus of study and to visualise it. As the study was based on the event experienced by one of the authors, their emotions were also incorporated in the

choice, development, and implementation of the methods. These will be described to reflect on how the authors and the participants of the project were situated within the research context as a reflexive approach (Pink 2013).

Secondly, the characteristics of the visual images that Mizuno recorded on his smartphone during the course of the project will be analysed and interpreted with reference to diary and interview data from each period. It will reveal how the smartphone camera was used in different modes.

Thirdly, from the viewpoint of Mizuno, who was both the researcher and the subject of the project, the findings and implications of visualising the experience of life transition as a family caregiver will be elaborated.

Lastly, the authors will discuss how we can understand and visualise the life transitions experienced by family caregivers, given that smartphones and social media are a part of everyday life for many people nowadays.

Methodological foundations and their applications in the project

1) Design research using smartphones

Mizuno decided to record himself and his family's life using his smartphone camera when he was informed of his wife's cancer in May 2017. His underlying habits and identity as a design researcher may have motivated him to record his daily life when he had to face his wife's unexpected disease and the associated changes in his family.

Design research is considered as a systematic enquiry into the design process. Its primary objective is to generate a new body of knowledge that contributes to better design, whether it is an object, service or system. In making prototypes, employing ethnographic research on users to understand their needs since user-centred design (as discussed by Norman and Draper 1986) became one of the main focus in the design research field. Accordingly, ethnographic methods are adopted in some cases, but speed is required in the industry-driven design context. In this sense, the stimulation and development of distinctive research methods called design ethnography (such as IDEO's design method cards) is required to capture the essence of user experience in a short period of time.

On top of understanding users, design research is also used to help designers generate imaginative artefacts. Such distinctive approaches on exploring users include 'Cultural Probe' (Gaver, Dunne, and Pacenti 1999), and more recently 'Design Documentaries' (Raijmakers, Gaver, and Bishay 2006), which attempt to illustrate the lives of users through the methods developed in documentary filmmaking. However, with the improved functionality and communication speed of smartphones, it has become no longer necessary for the researcher him/herself to physically go to the site or to provide a camera to the subject, which would be used as the 'Cultural Probe'. For example, user research that adapts a 'mobile ethnography' method (Segelström and Holmlid 2012) has emerged, such as sending out text messages to research participants on their smartphones, asking them to capture a video or photo, and then immediately sending these back to the researcher.

For years, in his role as a design researcher, Mizuno has been researching and practicing methods to understand users' lives via smartphones and cameras. He decided to record his and his family's life as a subject of research using his smartphone camera when his wife was diagnosed with stomach cancer during her last month of pregnancy. Smartphones are small in scale compared to general cameras and are commonly owned by many, which makes it easier to use them to shoot without making others uncomfortable. Shooting with a smartphone was easier and less stressful than a single-lens reflex camera or a video camera, so he could keep recording daily.

In the beginning, Mizuno did not have a clear objective, goal, or idea about the kind of research project he wanted to realise through the daily recordings of his family's life via his smartphone. Nor did he make an exact schedule of the research project. The manner in which his wife's disease was diagnosed and how circumstances related to his family changed was unpredictable. The project began in an autoethnographic way with Mizuno single-handedly recording the unpredictable situation.

In the first year he started recording, circumstances involving his family dramatically changed. Mie gave birth to a 2,900-gm baby boy on 1 June 2017. He was named Terasu. When it was decided that Mie would undergo a total stomach removal operation, her role changed from 'an expectant woman' to 'a cancer patient'. However, the operating surgeon told Mizuno that it was impossible to remove the entire stomach—she was on stage 4 cancer, not on stage 2 as the doctor had first anticipated, and instead

a bypass surgery was performed to help her provisionally regain bowel functions so that she could eat. The operation that was carried out for livelihood rehabilitation ended without any problem. Mie began to eat, starting with rice water and gradually moving on to rice porridge.

It was decided that Mie would return to the hospital to receive oncological treatment after leaving the hospital early in July 2017. As side effects exert mental and physical loads on patients, they had to leave Terasu in an infant home. The Child Welfare Act Article 37 states that infant homes should be facilities intended for admitting and fostering infants (including toddlers in cases where it is particularly necessary to ensure a steady living environment or due to other reasons of healthcare), as well as to provide consultations and additional assistance to those who have left (Ministry of Justice, Japan, 2009). Infant homes have been supporting babies and infants who cannot live with their families due to various family circumstances for more than 70 years in Japan (National Council of Homes for Infants Japan, 2019).

Mizuno and Mie could not get parenting support from either of their parents. Their parents live far from them and are at an advanced age. This forced them to rely on the infant home, which turned out to be a saving grace for Mizuno, who was bewildered about how he could raise new-born Terasu while balancing the need to support Mie's fight against the disease, work, and do household chores. However, Mie was not about to give up on child-rearing even though they had left Terasu at the infant home. She wished to raise Terasu herself as much as possible, bringing Terasu home on a regular basis. Terasu had been her long-cherished desire. Mizuno limited his work to raise Terasu with Mie as much as he could, especially when the side effects of her anticancer drug were mild. The period at the end of 2017 leading up to the New Year was particularly hectic, with Mie entering and exiting the emergency room due to her weakening physical condition as a result of a compromised immune system. Mie often caught colds and spent more days sleeping due to the side effects of anticancer drugs. Meanwhile, Terasu grew up quickly and healthily, weighing over 10 kg, progressing from a new-born baby to an infant. In March 2018, the family travelled to Kyoto to spend some blessed time with friends.

On 3 June 2018, Mizuno's family celebrated Terasu's first birthday at Mie's parents' home. Mie baked a special cake for Terasu. Terasu devoured it, however, Mie could not eat festive meals anymore. On 8 June, Mie was admitted to the hospital due to impaired liver function. Terasu was to spend more time at the infant home and go out only for a limited time when Mizuno went to see Mie at the hospital. On 27 June 2018, the attending doctor described Mie's disease as 'advanced stomach cancer with peritoneal dissemination' in her report during a meeting. He said he could do nothing further. A nurse who had specialised in palliative care joined the meeting. Around this time, Mizuno's work-life balance was disrupted, and he began to hear a ringing sound in his ears and had stomach aches caused by excessive stress.

2) Doing mobile visual ethnography and its variation process

On 28 June 2018, the very next day that Mizuno was told by the doctor that treatment for Mie was futile, Mizuno shared his situation to his sub-supervising PhD student at that time, Ohashi (the first author) and suggested to start a research project on his case. Ohashi was conducting her PhD project based on her interests in people's everyday experiences and practices of mobilities (Urry 2007; Büscher et al. 2011). The objective of her project was to understand and visualise how cross-border migrants in Japan communicate and maintain relationships with their family members abroad and how they live in the transnational lifeworld based on the methodology of visual ethnography (Pink 2013). Before commencing her PhD research project, she had completed a programme in Documentary Filmmaking at a film school. Thus, for her project, she combined her knowledge and skills of documentary filmmaking with visual ethnography methodologies. Ohashi had created a documentary by doing ethnographic fieldwork for over a year with each of her five research participants. In the process, she focused on the use of reflexive, collaborative, and participatory methods (Pink 2013).

As soon as Ohashi heard about Mizuno's situation, she responded with eagerness to start a research project with him. A month after Ohashi was informed of Mizuno's situation, when she had almost finished her doctoral dissertation, she embarked on this new project with Mizuno. The authors called this project 'X'. Neither of them knew how it would evolve; they would just keep working on it even though there was no budget.

Mizuno explained the project to Mie and obtained her permission to take photos and videos, and to use them to produce research-creation. Mie had long been aware of Mizuno's approach to design

research. She had also heard from Mizuno that Ohashi had been making documentary films in her research. On this basis, she agreed to be the subject of their research and did not ask them any questions or make any suggestions about the way in which she would be filmed or the treatment of the photographs and videos.

On 7 August 2018, Ohashi adopted a ‘mobile method’ discussed by Jirón (2011) to understand Mizuno’s everyday life. It is an ethnographic shadowing approach and Jirón (2011) elaborates on how this mobile method is valuable to get closer to people’s everyday experiences and practices of mobilities. Around that time, Mizuno frequently travelled back and forth by car between his home, the university he was working at, the infant home Terasu was living in, and Mie’s hospital. As Jirón (2011) had done with her research participants, Ohashi accompanied Mizuno, observing the way he experienced his journey between his home, university, the infant home, and the hospital and collaboratively reflecting on his experiences. This journey was filmed and photographed during the shadowing process and was reflected collaboratively using the visual images afterwards. In light of this, this method could be called ‘mobile visual ethnography’.

On this day, Mizuno worked at the university campus until noon, and then went to the infant home to pick up Terasu to bring him to the hospital. Mizuno introduced Ohashi to the staff at the infant home as a friend, however, the staff warned that Ohashi should have registered beforehand. As aforementioned, infant homes care for children who cannot live with their families due to various reasons. Thus, visitors are strictly controlled, and only those who are permitted may enter. After leaving the infant home, the authors and Terasu went to the hospital. Ohashi met Mie for the first time. Ohashi became nervous because she did not know how to behave in this peculiar situation, specifically in the patient’s bedroom, with Mie struggling against cancer. Mie greeted Ohashi with a smile and offered her some sweets. She looked skinny and could hardly talk, walk, or move. Ohashi could never bring herself to talk about the research project to Mie. Ohashi also felt uncomfortable pointing her camera at Mie, even though Mie had given permission to film her. The only picture she managed to take in the hospital was of Mizuno, Mie, and Terasu spending time together in a children’s area. Ohashi took this photo because she thought it was valuable as a record for the family, not as a part of the research. Mie appeared to be in pain and experiencing breathing difficulties, while Terasu was lively and playing with toys. After some time, Mizuno let Mie rest and left the hospital to bring Terasu back to the infant home.

Together, Mizuno and Ohashi reflected on the day and discussed how to move forward with the project. Ohashi said it would be difficult for her to directly photograph/film Mizuno’s family—including Mie. After meeting Mie, she thought that Mie had very limited time and physical strength, and that Mie would probably want to focus on spending time with her family too. Ohashi wanted to avoid exhausting Mie’s limited time and strength by staying in the lifeworld of Mizuno’s family for research purposes. Thus, Ohashi asked Mizuno to keep an open-styled ‘time-space diary’ in addition to photos and videos of his daily life. A ‘time-space diary’ is a mobile method that uncovers people’s modes of movement (Haldrup 2011). In the diaries, he was asked to describe time, locations, his activities, and thoughts. Mizuno and Ohashi began to share time-space diaries and visual images taken by Mizuno’s smartphone camera on Google Drive and to have weekly interview sessions to collaboratively reflect on the files.

3) Making an ethnographic documentary film ‘Transition’

In just one year, Mie transformed from an expectant mother, a mother, a cancer patient, to one who needed care. Terasu transformed from a new-born baby, an infant, to a toddler. Mizuno became a father to his son and a caregiver of his wife with cancer. The apartment the family lived in together became a place where Mizuno slept during intervals of coming and going to and from the hospital, infant home, and his workplace after Terasu was born. The apartment also became a place for the whole family to live together for a short period when Mie’s condition was better and was discharged from the hospital. In September 2018, it became a place to care for Mie till the end.

Mie passed away on 19 September 2018, a week after she began her final recuperation at home. Mie’s loss made Mizuno a widower and a single father. Subsequently Mizuno’s role transitioned, and environmental transition also occurred rapidly. Mizuno decided to move to Kyoto City. Kyoto is where Mizuno and Mie had lived for many years, with close friends who could support his future life. He needed a social network, not only for work, but also to raise Terasu by himself while working. After securing a new job, he found a place to live and a nursery for Terasu with the help of friends. Mizuno

and Terasu moved to Kyoto in March 2019. In total, Ohashi and Mizuno had 28 interview sessions from the beginning of the project until Mizuno settled in Kyoto in May 2019.

According to McNiff (2018), artistic expression offers modes of communication that are inaccessible to linear and logical reason and language. The authors felt that by making a documentary film, they could engage and express the rapid life transition experienced by Mizuno. Several documentaries were used as references in the making of the film. One of the most thought-provoking films was 'Tarnation' (Caouette 2003). Caouette composed his film as a collage-like combination of home videos, snapshots that he had taken since he was 11 years old. The film was made using only iMovie, a free video editing software that comes with the purchase of an Apple computer. The authors considered that Caouette's work is important because it shows that filmmaking can be seen as a way of reflecting on one's own lifeworld, and that there are tools that make it possible to visualise one's experiences without specialised skills.

The authors edited the film by using daily photographs and videos taken by Mizuno's smartphone between May 2017 and May 2019. Photographs and videos by Ohashi and Mizuno's friends were also included in certain scenes. Ohashi edited all the materials, referring to the 28 interview sessions they had together, with interpretations of each photograph and video by Mizuno in mind. As Banks (2007: 96) suggested, Ohashi sought to 'work with images and let them speak for themselves as it were, rather than trying to force them to conform to a predetermined intellectual agenda'. To express Mizuno's feelings and texture in his daily life as faithfully and accurately as possible, decisions such as which photographs and videos were used, how long they were used, in which order, if background music was used instead of narration, etc. were made based on the interview sessions. In addition, from the point of view of 'dignity-in-outcome' (Langmann and Pick 2014), careful attention was paid to protect the dignity of the subjects in the film, especially of deceased Mie.

In the editing process, Ohashi shared a rough cut of the documentary with Mizuno and Kato (the adviser of this project) via online communication tools including video calls and messages, and finalised the film based on discussions they had. The film was titled 'Transition'.¹ The film was selected for the IDFA Competition for Short Documentary of the 32nd edition of International Documentary Film Festival Amsterdam and also for The Japanese Film Festival Nippon Connection 2020 'NIPPON DOCS'.

Analysis of images

The authors analysed the 1,921 photo and video files taken by Mizuno with his smartphone and shared them with Ohashi on Google Drive. Firstly, the subjects of all the files were written down. After that, the background and intention of the shoot were interpreted. By analysing and interpreting the visual images, with reference to diary entries and interview data from each period, it was found that the smartphone camera was used in different modes at five different periods. The results of the analysis are given in the table, and the details are described below.

¹ It is available at a private URL on Vimeo: <https://vimeo.com/369453515/db2680dff>.

| Period | Events during this period | Number of photo files | Number of video files | Modes of the use of smartphone camera |
|--|---|-----------------------|-----------------------|--|
| 1. From May 2017 to May 2018 | -Diagnosis of Mie's stomach cancer -Birth of Mizuno and Mie's son, Terasu | 351 | 68 | -Used as a tool for creating family photo albums |
| 2. From June 2018 to 19 September 2018 | -Progression of Mie's stomach cancer -Start of continuous use of the infant home -Mie's hospitalisation and discharge -Mie's passing at home | 184 | 61 | -Used as a tool for creating family photo albums -Used as a tool for recording the changes in the family's living conditions for ethical reason |
| 3. From 20 September 2018 to early November 2018 | -Mie's funeral -Cleaning up the apartment -Administrative procedures after Mie's death -Mizuno's preparation for his new job in Kyoto -Searching for a nursery school for Terasu in Kyoto -Mizuno's participation in an international conference in London | 304 | 52 | -Used as a tool for recording administrative procedures of Mizuno's life transitions |
| 4. From mid-November 2018 to December 2018 | -Start of Mizuno's treatment at a mental health clinic due to sleep disturbances and malnutrition -Scattering of Mie's ashes in the sea of Okinawa -Preparation for Mie's memorial gathering with friends | 129 | 133 | -Used as a tool for Mizuno to understand his own condition |
| 5. From January 2019 to May 2019 | -Mie's memorial gathering with friends -Mizuno's job change and move to Kyoto with Terasu | 365 | 274 | -Used as a tool for recording the changes in the family's living conditions on the move |

TABLE 1: Analysis of visual images recorded by Mizuno's smartphone camera

1) The first period: from May 2017 to May 2018

This period was very difficult for the family when they first discovered Mie's stomach cancer but at the same time the birth of Terasu brought great joy. The smartphone camera was a tool for creating family photo albums. Most of the photos and videos during this period are close-ups and up shots of Terasu. Sometimes Mie, their relatives and friends are also the subjects.

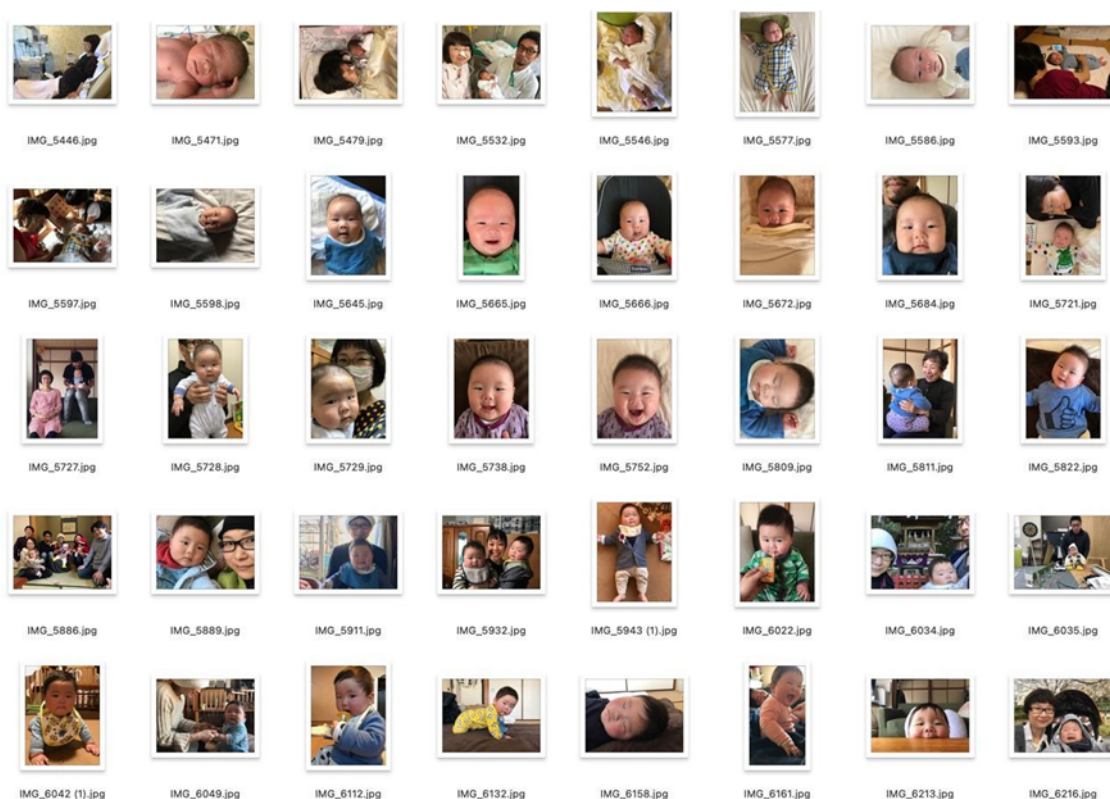


FIGURE 1: Screenshot of the thumbnails of a selection of the photo and video files taken during the first period

2) The second period: from June 2018 to 19 September 2018

By this time Mie's stomach cancer had progressed to a terminal stage and she was repeatedly in and out of hospital. Mizuno left Terasu at the infant home on an ongoing basis and took Terasu with him as

much as possible when he went to visit Mie at the hospital. During this period, Mie spent much of her time in hospital and Terasu in the infant home, while Mizuno was busy working and caring for both Mie and Terasu, shuttling back and forth between the hospital and the infant home.

From this time onwards, together with Ohashi, Mizuno began to consciously observe his own and his family's life as a research subject. The smartphone camera has become not only a tool for creating family photo albums, but also a tool for research. In the previous period, Terasu was the main subject, but in this period there are more photos and videos that show how the family's life has changed as a result of the progression of Mie's stomach cancer. The visual images clearly show that the family has been spending more time in the hospital room. Large cameras are not allowed in the hospital, and the areas where they can use cameras are mainly limited to Mie's private space. The smartphone camera was useful as a compact and mobile tool for research in situations where ethical considerations are required. In addition, Mizuno and Ohashi share the research interest in people's everyday experiences and practices of mobilities (Urry 2007; Büscher et al. 2011), which is also reflected in the photos and videos taken. For example, during this period, Mizuno delivered a variety of food to the hospital room in order to fulfil the wishes of Mie, who was gradually becoming immobile. These foods were photographed.

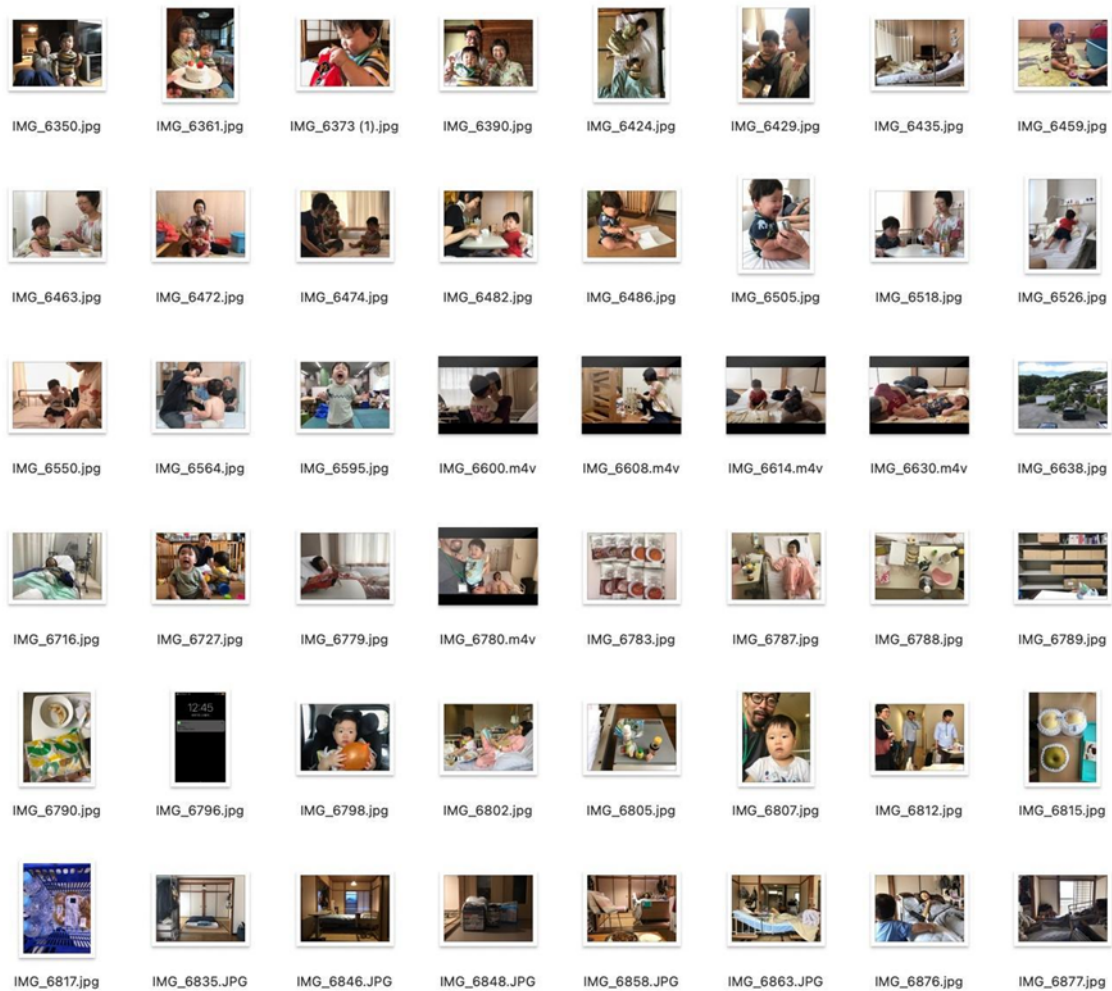


FIGURE 2: Screenshot of the thumbnails of a selection of the photo and video files taken during the second period

3) The third period: from 20 September 2018 to early November 2018

Mizuno's life changed drastically after Mie passed away. During this period, there was no time to grieve. He had to organise the funeral, tidy up the room where Mie had been taken care of, and work hard to complete insurance and municipal formalities. In order to raise Terasu on his own as a single father, Mizuno decided that he needed to move to Kyoto, where many of Mie and Mizuno's mutual

friends live. Mizuno began making preparations to change his job and to move to Kyoto. At the end of this period, he participated in an international conference in London, which was important for Mizuno as a researcher.

During this period, the smartphone camera was not a tool for creating family photo albums. It became a tool for recording administrative procedures of Mizuno's life transitions.

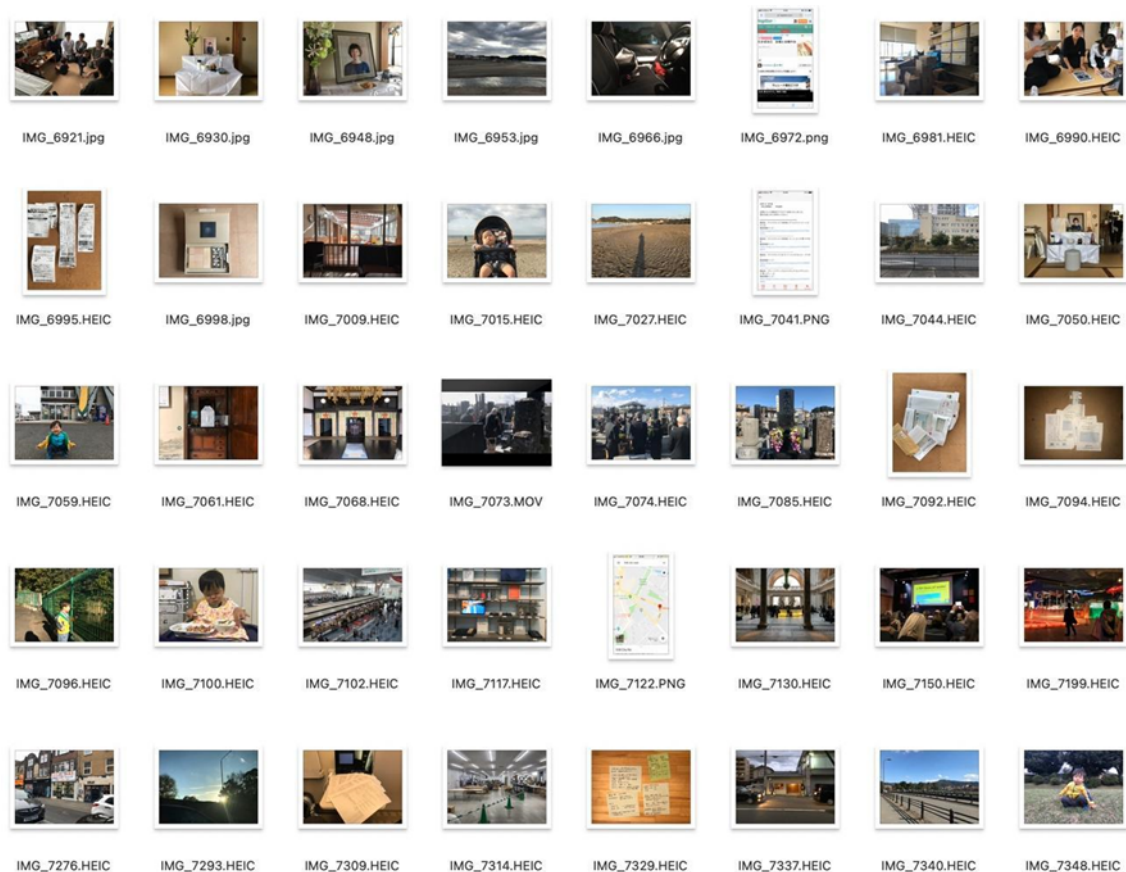


FIGURE 3: Screenshot of the thumbnails of a selection of the photo and video files taken during the third period

4) The fourth period: from mid-November 2018 to December 2018

In the two months immediately following Mie's death, Mizuno was very busy, without stopping, with paperwork, cleaning up the apartment and rebuilding his life. After a short break from his busy schedule, he went to the sea in Okinawa and scattered Mie's ashes there. This was where she had wished to go before her death. It gave him time to face Mie's death. On the day he scattered Mie's ashes, Mizuno took a photograph of himself in his suit reflected in the mirror. It was to record how he had dealt with Mie's death.

The memorial gathering of Mie was to be held at the beginning of the next year. Mizuno and his friends were preparing for it. For the memorial gathering, Mizuno reflected on his memories of Mie, meeting and marrying her, her pregnancy and childbirth, her illness and death. He put these memories into words. The process of looking back and writing about his memories of Mie was a greater emotional burden for him than he imagined. At this time, he was suffering from sleep disorders and malnutrition. This is reflected in the photos and videos taken during this period. The photographs of empty parks and streets at night were taken when he couldn't sleep and went for a walk in the middle of the night. These photographs do not represent the observable events of the time, but rather the condition of his body and mind. The smartphone camera has become a tool for the authors to understand his condition. At an interview session, Ohashi found out about Mizuno's condition and suggested that he go to a mental health clinic. Mizuno followed the suggestion and started to go to a mental health clinic during this period.

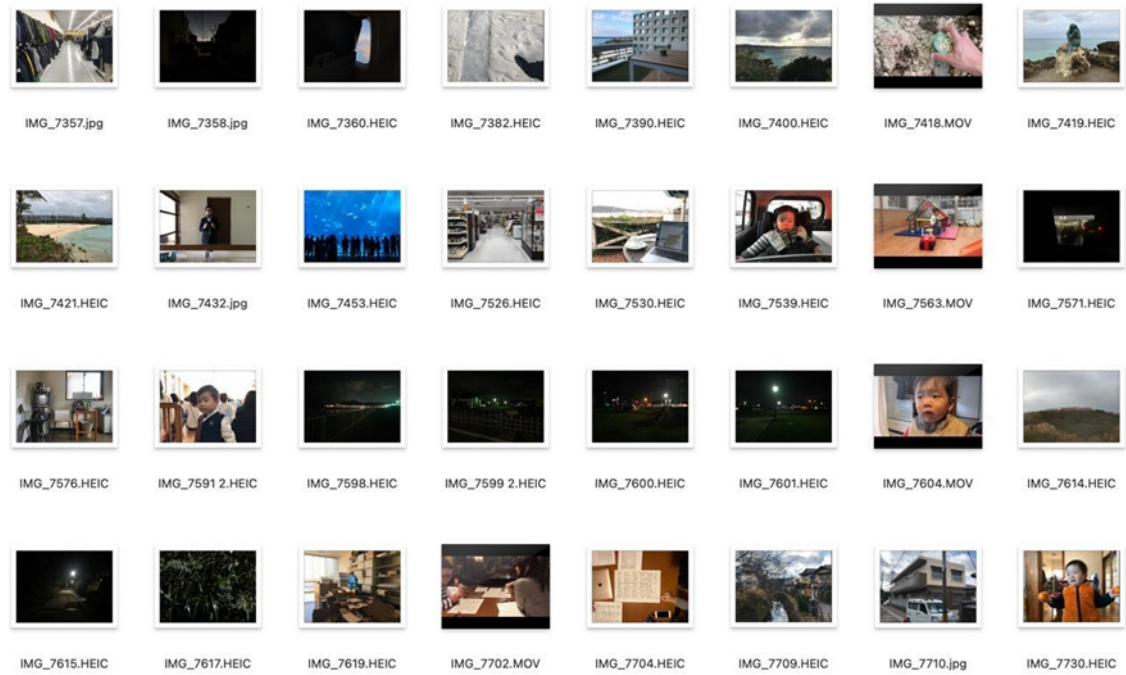


FIGURE 4: Screenshot of the thumbnails of a selection of the photo and video files taken during the fourth period

5) The fifth period: from January 2019 to May 2019

Mie's memorial gathering was held at the beginning of January. Around 200 of Mizuno and Mie's relatives, friends and colleagues attended the gathering. The participants ate a feast together and talked about their memories of Mie. It was also an opportunity to see the supporters of Mizuno and Terasu in their future life. In January, Mizuno confirmed his offer to work at a university in Kyoto from April. Accordingly, preparations were made for Terasu's admission to nursery school and for their move to Kyoto. The photos and videos from this period show Mizuno's preparations to start a new life in a new place, together with Terasu as a single father. The smartphone camera was used as a tool for recording the changes in their living conditions on the move. In Kyoto, Mizuno's workplace, Terasu's nursery school, and their apartment are in close proximity to each other. After moving, Mizuno sold his car and started to travel by bicycle and on foot. Old friends who live in Kyoto have come to support Mizuno in raising Terasu. These are reflected in the photos and videos.

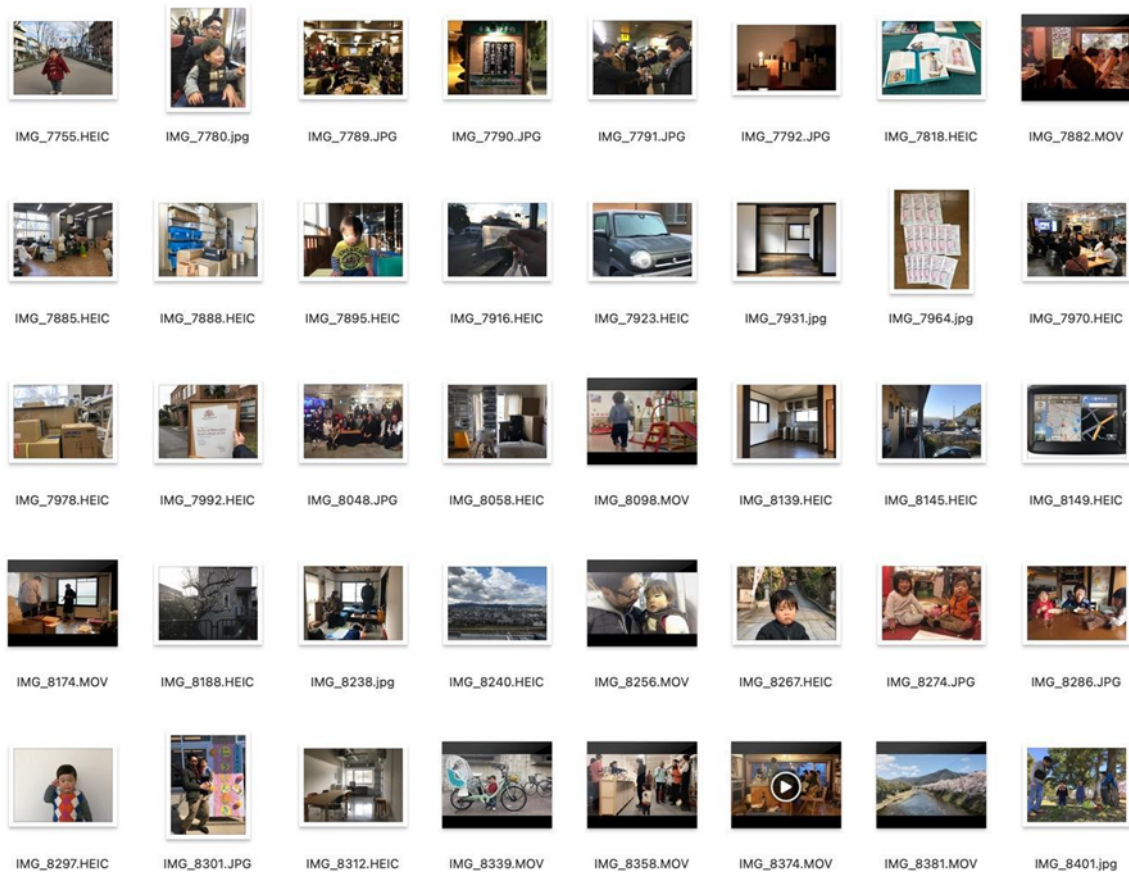


FIGURE 5: Screenshot of the thumbnails of a selection of the photo and video files taken during the fifth period

Findings and implications from the project

In this section, the findings and implications of visualising the experience of life transitions as a family caregiver will be elaborated from the viewpoint of Mizuno, who was both the researcher and subject of the project. There are three main points: the impact on Mizuno as a family caregiver, the impact on his family and lastly, expected impact on society. This paper has been written in the third person so far, but this section will be written by Mizuno in the first person.

1) The impact on Mizuno as a family caregiver

In this project, I was able to understand my own grieving process by objectifying myself in difficult situations. In other words, it became an autoethnography as a process of self-care and recovery. As a collaborative research project, the dialogue with Ohashi helped me to objectify my situation and to gain an analytical perspective. As the focus of the research was not a past event, but an ongoing event that was happening to me, the dialogue also led to new ways of thinking that brought about changes in my situation. This is exemplified by the case described in the fourth period, where Ohashi's advice led me to go to a mental health clinic. My psychological recovery process was accelerated by regular interview sessions, where I shared my lifeworld with another person/researcher and as a result, empathic communication occurred.

In addition, I was able to get feedback from others by showing my own lifeworld as a documentary film. Some of the people who attended the screening shared their own family experiences and bereavement. In this way, empathic communication with others (including strangers) occurred and I was able to reaffirm that bereavement in the family is something that can happen to anyone and is an inevitable event in life.

2) The impact on Mizuno's family

As already mentioned, Mie had given us permission to take photographs and videos and to use them to produce research-creation before she passed away. Mie's permission was based on her understanding of my research; but it was certainly not the only reason. Mie was a writer, illustrator, and editor before she became ill. After she gave birth and found out she had terminal cancer, she started to make a picture book for our son, Terasu. Having worked in the field of visual expression, she wanted to create a medium that would allow her to convey her thoughts to our son even after her death. It was with this in mind that she never once refused or questioned being photographed or filmed in this project. In fact, our son has already watched this film several times. It serves as a medium for him to know how his mother lived after he was born and how she treated and interacted with him in her final years.

3) Expected impact on society

As discussed in the beginning of this paper, the life transitions of family caregivers who became young widowers during the infant-care period of their child(ren) are scarcely documented in the academic realm in Japan. As a result, there is a lack of understanding of the lifeworld of those who became single fathers after the death of their partners, and the necessary social support is not in place. As a single father myself, I found it difficult to receive the social support I required after the death of my partner, and experienced the complicated procedures of private and governmental services related to care and medical insurance. By opening the research-creation of this project to the public, I hope to increase the understanding of this problem and to improve the situation for people who may experience the same.

Concluding discussion

In this paper, the process of how the authors applied multiple methodologies to develop the research project to understand and visualise the life transitions experienced by Mizuno as a family caregiver of a cancer patient, was elaborated. Then, the characteristics of the visual images that Mizuno recorded on his smartphone during the course of the project were analysed. In this project, Mizuno was both the researcher and the subject of the project. He reflected his knowledge and experiences as a researcher in his own behaviour as a research subject. This particular condition has certainly made this project possible in a significant way. However, the authors believe that the findings can be applied to other projects that seek to understand and visualise the details of life transitions experienced by family caregivers. In this final section, the research findings will be used to discuss points that can be applied to other projects.

As already described in detail, in the first period of the project, Mizuno worked alone, using a smartphone camera to record the changes in his family's life. From the second period, the role of the smartphone camera gradually changed as he began to do collaborative research with Ohashi. Beginning from this period, the authors also implemented specific research activities, which were carried out almost every week until the end of the project. By repeating this set of weekly research activities, the understanding of Mizuno's experience of life transitions as a family caregiver was deepened through dialogue. The smartphone camera became an important research tool for recording and sharing both the objective facts about Mizuno's life transitions and his physical and emotional condition while experiencing them. The specific actions entailed in the set of weekly research activities are shown in the diagram so that they can be applied to other projects. To simplify the model, Mizuno's position in the project is referred to as 'participant (research participant)' and Ohashi's position is referred to as 'researcher' in the diagram.

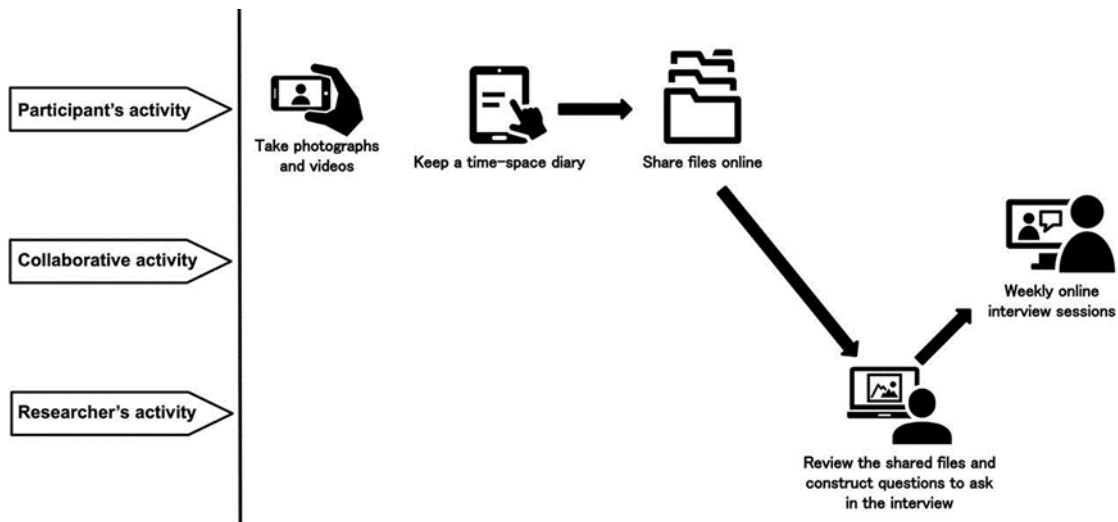


FIGURE 6: Set of weekly research activities to understand the life transitions experienced by family caregivers

Taking photos and videos with a smartphone camera has become an everyday activity for many people. In this sense, the activities shown in the diagram will not be too much of a burden for those who participate in a project. If the researcher prepares in advance a simple diary format and an online folder for sharing photos and videos, this will facilitate the participants' activities and increase the feasibility of the project. As this project has shown, it is difficult for researchers to understand family caregivers' lifeworld by observing and interviewing them in the field because of ethical concerns. This method will help to clarify the family caregivers' lifeworld remotely and in detail.

This project produced 'Transition', a film that was made using visual images shared during the weekly research activities. The process of making the film is shown in the diagram below.

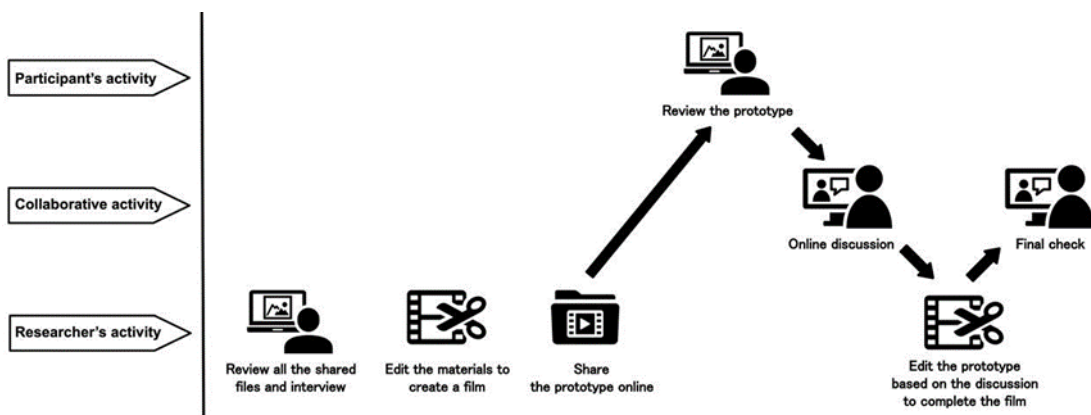


FIGURE 7: Process of making the film 'Transition' using visual images shared through the weekly research activities

In recent years, there have been applications that automatically generate a video of personal memories using photos and videos taken with a smartphone camera. However, these videos generated by such applications are not edited based on a deep understanding of the meaning of each photograph or video. Therefore, they would be incomprehensible to anyone other than those who are close to the owner of the smartphone. As mentioned earlier, the film 'Transition' was selected for the international film festivals. Referring to the two diagrams above (Figure 6, 7), this appears to be due to the fact that the film was made in an interactive and collaborative process as a work to be opened up to others. In addition to screenings at the international film festivals, the authors also organised screenings and workshops in Tokyo. Discussions with the audience covered not only the life transitions experienced by Mizuno as a family caregiver, but also topics such as the design of public services for family caregivers, ethical issues in researching family caregivers, and issues of privacy in photography and film.

In Japan, there are still very few opportunities for family caregivers of cancer patients who have

experienced rapid and harsh life transitions to share and talk about their experiences. People are not only likely to become cancer patients themselves, but even more so to be in a position where they are required to care for a family member who has become a cancer patient. The authors hope that recording and visualising the experiences will stimulate discussion to create a better social system that supports the recovery of family caregivers from such difficult experiences.

REFERENCES

BANKS, Marcus

2007 *Using Visual Data in Qualitative Research*. London: Sage Publications.

BÜSCHER, Monika - URRY, John - WITCHGER, Katian (eds)

2011 *Mobile Methods*. New York: Routledge.

CAOQUETTE, Jonathan

2003 *Tarnation*. Produced by Jonathan Caouette and Stephen Winter. 91 min. United States.

CYBER AGENT, INC.

2019 Press Release (September, 13-2019) . Accessed online, August, 29-2021:

<https://www.cyberagent.co.jp/news/detail/id=23617>

CYBER AGENT, INC.

2021 Ameba Official Genre. Accessed online, August, 29-2021:

<https://blogger.ameba.jp/>

GAVER, William - DUNNE, Anthony - PACENTI, Elena

1999 Design: Cultural Probes. *Interactions* (6): 21-29.

HALDRUP, Michael

2011 Choreographies of leisure mobilities. In *Mobile Methods*. Monika Büscher, John Urry and Katian Witchger (eds). New York: Routledge. Pp. 54-69.

JIRÓN, Paola

2011 On becoming 'la sombra/the shadow'. In *Mobile Methods*. Monika Büscher, John Urry and Katian Witchger (eds). New York: Routledge. Pp. 36-51.

KONDO, Makiko - SATO, Reiko

2007 Sufferings of Middle-aged Men with Minor Children Who Have Lost Their Spouses to Cancer. *Journal of Chiba Academy of Nursing Science*, 13(1): 94-101.

LANGMANN, Sten - PICK, David

2014 Dignity and ethics in research photography. *International Journal of Social Research Methodology*, 17(6): 709-721.

LEE, Kyoung won

2019 Divorce and Bereavement with Spouse and the Actual Conditions of Children's Lives. *Journal of Social Security Research*, 4(1): 4-19.

- MATSUSHITA, Toshiko - NOGUCHI, Wataru - KOBAYASHI, Mika - MATSUDA, Ayako - MATSUSHIMA, Eisuke
2010 The Psychological Burden and Care/support for the Family Members of Cancer Patients: An investigation through an Internet survey. *Japanese Journal of General Hospital Psychiatry*, 22(4): 373-382.
- MCNIFF, Shaun
2018 Using Digital Media in Art-Based Research. In *The Handbook of Art Therapy and Digital Technology*. Cathy Malchiodi (ed). London: Jessica Kingsley Publishers. Pp. 332-345.
- MINISTRY OF HEALTH, LABOUR AND WELFARE, Japan
2017 Nationwide Survey on Single Parent Households, v Accessed online, December, 29-2019:
<https://www.mhlw.go.jp/file/04-Houdouhappyou-11923000-Kodomokateikyoku-Kateifukishika/0000188136.pdf>
- MINISTRY OF HEALTH, LABOUR AND WELFARE, Japan
2018 Vital Statistics, Accessed online, December, 29-2019:
<https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/geppo/nengai18/dl/gaikyou30.pdf>
- MINISTRY OF JUSTICE, Japan
2009 Child Welfare Act. Accessed online, December, 29-2019:
<http://www.japaneselawtranslation.go.jp/law/detail/?id=11&vm=04&re=01&new=1>
- MUTA, Reiko
2018 Development of a support guide for families of terminally ill cancer patients and verification of its usefulness for nurses in general wards (The original title is in Japanese). Accessed online, August, 29-2021:
[https://ir.lib.hiroshima-u.ac.jp/ja/list/doctoral_thesis/%E5%8D%9A%E5%A3%AB\(%E7%9C%8B%E8%AD%B7%E5%AD%A6\)/item/32025](https://ir.lib.hiroshima-u.ac.jp/ja/list/doctoral_thesis/%E5%8D%9A%E5%A3%AB(%E7%9C%8B%E8%AD%B7%E5%AD%A6)/item/32025)
- NATIONAL CANCER CENTER JAPAN
2019 Latest Cancer Statistics. Available, Accessed online, December, 29-2019:
https://ganjoho.jp/reg_stat/statistics/stat/summary.html
- NATIONAL COUNCIL OF HOMES FOR INFANTS JAPAN
2019 About Infant homes. Accessed online, December, 29-2019:
<https://nyujiin.gr.jp/about/>
- NORMAN, Donald - DRAPER, Stephen (eds)
1986 *User Centered System Design: New Perspectives on Human-computer Interaction*. CRC Press.
- ONISHI, Hideki
2009 Intervention and Psychological Care for the Family Caregivers of Cancer Patients. *Psychiatry et neurologia Japonica*, 111(1): 79-84.
- PARDO, Rebeca - MORCATE Montse
2016 Illness, death and grief: the daily experience of viewing and sharing digital images. In *Digital Photography and Everyday Life: Empirical Studies on Material Visual Practices*. Edgar Gomez Cruz and Asko Lehmuskallio (eds). Routledge. Pp. 70-84.
- PINK, Sarah
2013 *Doing Visual Ethnography THIRD EDITION*. London: Sage Publications.
- RAIJMAKERS, Bas - GAVER, William - BISHAY, Jon
2006 Design documentaries: Inspiring design research through documentary film. *Proceedings of the Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques*, DIS. 2006: 229-238.
- SAWAI, Atsushi
2002 'Tabooed Death' Revisited. *Japanese sociological review*, 53(1): 118-134.

SEGELSTRÖM, Fabian - HOLMLID, Stefan

2012 One Case, Three Ethnographic Styles: Exploring different ethnographic approaches to the same broad brief.
Ethnographic Praxis in Industry Conference Proceedings 2012: 48-62.

SHIRAKAWA, Ayumi

2015 A Literature Review about the Psychosocial Influence of the Widowers after the Bereavement in Japan.
Journal of Japan Academy of Community Health Nursing, 18(1): 102-109.

URRY, John

2007 *Mobilities*. Cambridge: Polity Press.