

Life:Moving

An Exhibition of Films by Patients at
John Taylor Hospice,
Birmingham, UK



Photo credit: Andrew Burchell by Warren Pitts

From the research project:
'Digital Technology and Human Vulnerability:
Towards an Ethical Praxis'
<https://lifemoving.org/>

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Life:Moving is an exhibition of films made by participants from John Taylor Hospice in Erdington over a six month period from October 2016-April 2017. The films were made as part of a collaborative and interdisciplinary research project based at the University of Birmingham and you can find out more about it in the pages that follow. Its broad aim is to challenge society's misconceptions about terminal illness by giving those experiencing it the opportunity to tell their own stories, and by bringing these stories to a wider audience. In so doing, the project seeks to better understand the potential of digital film to serve the best interests of the vulnerable lives it so often depicts and then disseminates.

Various questions underpinned this research. What were the most pressing issues for the participants in making these films? Which filmmaking tool – a smart phone, tablet or SLR camera - would best serve their creative interests and practical needs? In the age of the selfie, how would individuals with a range of physical restrictions but a lot to say represent themselves and bring personal and often difficult issues to public attention? And how would the research team support this and create an environment which respected the vulnerabilities of all those involved?

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THE RESEARCH:

The development of digital technologies in the last two decades has provided new possibilities for the recording, representation and sharing of profoundly private and rarely seen experiences of dying. Lighter less intrusive equipment (SLRs, smartphones, tablets, headcams) afford ever-greater intimacy and immediacy. Social justice film festivals, video advocacy organisations, news and campaigning agencies, citizen journalists, activists and vloggers develop and deliver footage and films about human vulnerability for a range of agendas and to ever greater numbers. At the same time, end of life policy reforms in the West over the last decade demand changes in repressive attitudes to death and dying and have increased cultural engagement and community and art involvement with this topic.

This colossal increase in our potential exposure to visual content on human suffering has been accompanied by only limited discussion of its ethical implications; of how we feel and think in relation to this often highly affecting content and how it opens up or closes down emotion, empathy or even action. Yet, digital technologies have transformed our encounter with vulnerability through their seemingly intimate and infinite capacity to stage the suffering of others: to capture the last breath of a Motor Neuron Disease victim or to stream the bodily impact of chemical warfare live to audiences on the other side of the world.

It is the understanding of just such an encounter that lies at the heart of the burgeoning field of ethical film research – to which this project contributes – and its discussion of how such representations block or, instead, might bolster human connection. However, this discussion has yet to engage fully with two specific areas. First, with how human connection is affected by the digital at the level of production – how digital technologies enable a film practice that creates new forms of intimacy, immediacy, agency and co-authorship for the subject and co-creator of the film. Second, with how human connection is affected by the digital at the level of reception – how digital modes, through which we engage with these representations (TV, the web, the smartphone, tablet or projection), impact our response to the vulnerable lives we are exposed to.

This research project has attempted to address these two areas whilst all the time pursuing greater knowledge of the ethical issues inherent to the endeavour. Drawing upon a range of disciplinary perspectives, we have sought to bring theory and practice together to better understand how digital technologies and the power of film might be harnessed to develop a film praxis sensitive to the different needs, interests and contexts of those in or making, watching, curating or sharing the digital material. We hope, that such a praxis, such a theory-informed practice, might communicate vulnerability in a way that dispels misrepresentation and, instead, forges human connection, and empowers its subjects, without compromise. In other words, without a

retrenching of the invulnerable gaze – with all its social and cultural specifications – that looks upon and remains untouched by the suffering of others.

It has been a privilege to collaborate on this project with John Taylor Hospice, the research team and, especially, the participants. We're indebted to Paddy and Jo, and the other staff and volunteers, at the day hospice in particular, for all their support. Funding is being pursued, currently, for a further tour of the exhibition that we might bring these films and the insights they share, and fuel, to new audiences. The project's findings are being presented in academic conferences in the UK and abroad and will inform academic publications and other research projects in the future.

Michele Aaron
Principal Investigator

THE RESEARCH TEAM:

Life:Moving has benefitted from a range of expertise provided by its research team. The multi-disciplinary team brought together a range of specialisms in film, human-computer interaction, Arts practice, curation, sociology and art therapy. The team consisted of:

Michele Aaron, Principal Investigator, Film Studies, University of Birmingham, Russell Beale, Co-Investigator, Computer Science, University of Birmingham; Briony Campbell, Professional Filmmaker; Jed Jerwood, Art Psychotherapist, John Taylor Hospice, Dr Cath Lambert, Co-Investigator, Sociology, University of Warwick; Dr Lisa Metherell, Co-Investigator, School of Art, Birmingham City University; Adrian Banting, Research Fellow.

THE PROCESS:

The project combined workshops at John Taylor Hospice with home visits to participants. The workshops, run by Michele, Briony and Adrian, provided participants with the critical and practical foundations with which to develop the ideas for their films. They also afforded the opportunity for everyone involved to share ideas about their own and each other's work and their experience more widely. Monthly review meetings with the larger team reflected upon the ethical issues emerging. Increasingly, they focused on the development of the exhibition. The films themselves were made with varying degrees of support by Briony Campbell. The exhibition showcases the work of the six participants and wouldn't have been possible without their collaboration, commitment and creativity.

THE EXHIBITION

Robert Homer

Rob is a keen artist and, more recently, poet. No stranger to the creative process, Rob's challenge was how to transfer this familiarity to the unknown medium of film and via a set of tools that were new to him. His priority was a 'warts and all' disclosure of his experience of cancer. In order to achieve this, he started by filming on his phone last thing at night and first thing in the morning, his worst and best times of the day. This hand-held recording captured the intensity and intimacy he was after but the quality was poor. These monologues would develop into the core of his film, but Rob went on to experiment with a higher quality SLR camera and time-lapse photography to provide other layers to his narrative of self-portraiture.



Fran Tierney

Fran's project is especially, and inevitably, indebted to technology. She uses Eyegaze, an eye-operated communication system, to speak

having lost the ability to use her own voice due to Motor Neurone Disease. But, as she pointed out in our first workshop, this computer-generated voice has no emotion. The challenge, then, for her and her aspiring-filmmaker son, Louis, was about how to fulfil Fran's wish to convey her feelings about her diagnosis and the implications on her family.



During a workshop that they attended together, Fran and Louis were introduced to the idea of using old photographs as a backdrop to storytelling. This proved a fruitful way for the family to engage with the project and to gather material that, together with footage taken by Louis, would become the visual accompaniment to the text that Fran wrote. The film was a collaboration between mother and son. Fran and Louis worked mostly independently: Fran on the script and Louis filming and editing.

Peter

Peter's approach to the project was shaped by his long-term love of both hiking and photography. He was clear from the start that his

film would be focused on these, and on invoking a sense of what he most missed doing now.



He recorded a voice-over and edited it together with his selection of photographs he had taken in the past to create a slideshow of landscapes that have influenced his character and offered him sustenance throughout his life. No longer being able to visit them, this film serves as a tribute to what they have given him. Unlike most of the other films in the exhibition, Peter recorded and edited his film independently.

Yussef and Haifa Ahmed

The film, 'The inspirational man and his Journey to one', is a collaboration between Youssef and his wife, Haifa, and Briony. When the project started, Youssef was already very close to the end of his life and would, in fact, die shortly afterwards. Haifa attended some of the early project workshops and she and Youssef had a keen sense of what they wanted the film to show; that it might reflect his beliefs and experiences through highlighting his musical and political activities and at the same

time provide an important record for their daughter Reem.

The challenge of this film was to find the right balance between the authorship and hopes of those involved in its creation and both respecting and privileging the wishes of Youssef. The film combines old and recent photographs and footage of musical performances, Youssef's final birthday and his funeral. It provides one of the narratives to emerge as part of his involvement in the project. Losing Youssef so early on, we were reluctant to fix his story without him. Therefore, in addition to presenting an edited film on the central projector, other clips and recordings, which were produced or selected by Youssef and Haifa as part of the project, are available on the touchtable.



In this way, other narratives about Youssef might emerge through your interaction with it.

Keisha Walker

Keen to learn new things, Keisha was determined to take part in the

project. Like some of the other participants, however, she found the process of filming and being filmed more exposing than she'd anticipated. As a result, it took time to find the tools that suited her and allowed her to say what she wanted to say and in a way that was both comfortable and authentic.



Interested, originally, in conveying her particular perspective as she moved through her world in a wheelchair, a GoPro seemed the ideal tool for her to either wear or attach to her chair. However, it proved too fiddly to mount or film with. Alternative solutions were required: the familiarity of her smart phone camera was revived through a Samsung tablet, and its intimacy through a high quality sound recorder to provide audio. A variety of technologies enabled Keisha to capture a range of her ideas and perspectives, and these have been worked together for the exhibition.

Andrew Burchell

Andrew's enthusiasm for the project came from his long-

standing interest in art and culture, strong views on life and death and the very limited opportunities he has for social or creative activities owing to significant physical constraints. Unexpected hospitalisations during the project presented further obstacles to realising all his aims for the film, but in collaboration with friends, Briony and the research team, images were selected and monologues captured and brought together into two final cuts.

The challenge here was about achieving a balance between Andrew's ambitions for the project, his wealth of ideas and what was possible. The final result was achieved primarily through Briony visiting Andrew at home, and recording him there with a digital SLR camera. Though Andrew wasn't able to be as involved in the project as he had hoped, his characteristic optimism – his friends from his time living in Kenya pronounced him a 'life-ist' - compelled him to give what he could. We recorded his thoughtful reflections on his experience of the care system and the heightened value that medical advances place on human life.

