The Mitori Project

End of life care in the United Kingdom and Japan - intersections in culture, practice and policy

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In the middle of August 2018, an unanticipated funding call from the UK Economic and Social Research Council (ESRC, with a tight deadline for submissions, seemed initially to have little appeal. Better perhaps to enjoy the end of summer and gear up for the academic year ahead. But as two colleagues with shared interests in end of life issues in our respective countries, we were quickly galvanised into action when we saw that the scheme in question invited scholars from Japan and the UK to come together in pursuit of greater collaboration.

The ESRC initiative was open to applicants from the social sciences and humanities, with no restriction on subject matter. A niche area like end of life care may have seemed unlikely to succeed in such a context, but we went ahead with our bid and learned later that year we had been successful, and could begin immediately. The subsequent work took place over just 15 months, during which we went on a fascinating shared journey that took us into new and deeply rewarding territory.

Mitori（看取り）is a Japanese word referring to the practice of accompanying someone towards the end of their life. Widely associated with end of life care in Japan, 'Mitori' provides an orientating concept to unlock deep cultural assumptions about where, how and in what circumstances people should die. It has some resonance with the concept of 'Watch with Me', developed by Cicely Saunders, as well as with the notion of 'accompaniment' that is found in western models of palliative care. Mitori particularly connotes careful or mindful watching, in the present. It is about being aware of what is happening, and staying with the dying person to the end. Drawing from these connotations and using a comparative approach, the Mitori Project has tried to instantiate a 'watching' brief on end of life issues in the UK and Japan, paying attention to deeper processes as well as surface tensions.

Our *aim* with Mitori has been to forge a new research agenda for end of life care in the two countries, building a team that could take it forward based on mutual learning and a comparative approach. Our project has brought together academics across disciplines to examine how care of people at the end of life is currently organised in the UK and Japan, exploring relevant cultural, demographic, professional and policy factors in two societies characterised by ageing populations, heavy demand on health and social care systems and changing social expectations about dying, death and bereavement.

Our *objectives* were threefold:

1. To identify key thematic areas of difference and commonality in end of life issues relating to Japan and the UK, paying special attention to the conceptual problems of comparison, in order to shape a new agenda for social science research on end of life care in the two countries.

2. To facilitate face to face meetings between the participants and create an active online and digital forum for the sharing of ideas and the development of collaborative work between team members, enabling us to build capacity for future working.

3. To create an outward facing presence through a website and the active use of social media platforms, thereby building a wider community of interest around the project and establishing pathways to impact, helping us to identify key stakeholders to engage as users and co-producers of future research.

Our *method* has consisted in establishing a core team, where six members – all early career researchers - have formed UK-Japan pairs, to work together on defined areas. Also in the core team are support staff with communications expertise and one postgraduate student. Beyond them, we have a number of more senior colleagues in the two countries, who have given advice and direction.

From the outset we were convinced that our approach could only be delivered through a multi-disciplinary lens. Our team therefore came to comprise perspectives from sociology, anthropology, philosophy, ethics, religious studies and service and policy evaluation. In the original application we identified three themes for exploration relating to end of life issues in the two countries: culture, practice and policy. These would be the foci for the research pairs, taking one theme each.

The culture theme was led by Yoshi Takata and Gitte Koksvik. From the myriad dimensions that could be explored, they concentrated their efforts on a pressing topic that had resonance in both countries – lonely dying. Through this the UK researchers were introduced to the phenomenon known as 'kodokushi' – lonely death, or dying alone (sometimes with no one aware and the body only discovered weeks or months later). It is estimated that c27,000 people die alone in this way each year in Japan, a figure which has doubled in the last 15 years. To what extent can such a trend be expected in the UK? There we found no direct parallel, and certainly not the same level of public awareness, but the researchers made a useful link to ideas about 'social death' that have been well described in the literature. This led them to explore how dying alone should be evaluated and what place it has in the cultural scripts of dying in the two countries.

Culture-specific beliefs, values and behaviours about end of life both constitute and complicate the organization and *practice* of end of life care. The practice theme, led by Marian Krawzyck and Haruka Hikasa, concentrated on Advance Care Planning (ACP), which emerged as a compelling field of end of life activity around which to build comparisons between the two cultures. They conducted a detailed analysis of approaches and methods in Scotland and Japan, focussing on public documents and guidelines and with a special emphasis on the language and imagery that is used. They found common themes in the concern to reduce medical costs and hospital admissions, as well as the tension between autonomy and control versus relational perspectives. But these over-arching aspects seem to give way at the national level to differences in the amount of information resources that are available, the varied links between ACP and medical records, and the direct and indirect connections to larger health policy goals.

The *policy* stream of work was led by Miho Tanaka and Chao Fang, who created a Policy Brief to summarise the dominant aspects of end of life policies and systems that exist in England and Japan. They suggest that on several dimensions, Japan has things to learn from England, including the need to: introduce national strategies and specific legislation on end of life care; clarify cost-saving for a sustainable system in future policy strategies; secure sufficient government funding to improve and promote spiritual care for dying people and bereavement care for their families; and ensure equal and easy access to end of life care for residents from non-Japanese backgrounds. Conversely, England can learn from Japan by: further emphasising the role of family carers in end of life care settings; improving communication between health and social care providers, as well as within communities to further enhance co-operation and flexibility of care provision; exploring a universal, instead of an income/need-based social care system; and further emphasising prevention services to make social care more sustainable.

Each of these areas relating to culture, practice and policy, is now being worked on for publication, and the policy brief is already available[1]. We believe it is a terrific result in a short time from people

who were previously complete strangers to one another and who fitted in their Mitori work alongside all their pre-existing commitments (our funds were for travel and meetings only).

This working together has been our greatest reward and also our biggest challenge. 'Light bulb' moments of discovery were much in evidence in our meetings, but at the same time we struggled with language barriers. We found that the translation services we bought in worked best with the researchers working in pairs, rather than in the full meetings. We were fortunate also that two non-Japanese members of our group were fluent in the language and had lived as students in the country for extended periods. They facilitated not only the academic discussion, but also the logistics and practicalities. We also filmed our time together and have already made short videos available about the work of Mitori[2] and similarly, we have blogged about the project, to useful effect.[3]

The highlights of our project were the two workshops where the team members were able to meet together face to face.

The first of these took place at the Dumfries Campus of the University of Glasgow in March 2019 and enabled us to get to know each other and make plans for the work ahead. We held a UK-Japan oriented death cafe in a local venue, spent an afternoon in a workshop at the nearby Allanton Peace Centre, founded in 1955 by the Japanese teacher, philosopher and poet Masahisa Goi, and visited sites of local interest. We then met for two days, with some invited guests to map out in detail the programme of work around the three themes. By the last session, everyone was clear about the direction of travel, and the early career pairs had each formed a work plan. During the week, the spring weather had brought forth the *sakura* on the cherry trees – much to the delight of the Japanese visitors. It seemed a good omen – the Mitori project was already blossoming!

The return visit took place when we all re-assembled in Shizuoka University in December 2019. Our meetings were held for the most part within sight of Mount Fuji, the beauty and constantly changing vistas of which, were absolutely uplifting. Now we visited a cancer support centre, Sachi House, which is inspired by the UK Maggie's Centres, and at which we took part in a discussion with staff, local clinicians and guests of the service. Next day we began the Mitori workshop and in the evening held a death café organised along local principles. As in Dumfries, we had a workshop session that was open to local clinicians, academics and members of the public. Most important of all, the research pairs were able to spend in-depth time together, working in detail on their shared tasks. The productivity was high and the sense of collaboration was palpable. We parted from each other with a sense of sadness at something concluding, but also optimistic about the good things that would result from the work and the potential for new, shared projects – one of which, on end of life experiences of dying migrants in the two countries, is already taking shape.

We are writing this editorial as the COVID-19 pandemic is all around us. It was not on our radar when we met in Japan in December 2019 and unfortunately it led to the cancellation of an end of project event we had planned to hold in the Embassy of Japan, in London in March. But during their December visit, the British team did note and were curious about the use of facemasks in Japanese culture, and one even adopted the practice in our meetings due to a cold. Now, as we write, in late March 2020, there is growing discussion about how Japan has had so few cases and deaths from Coronavirus. One line of reasoning relates to the almost universal and culturally normative use of masks among the public – which may not only reduce transmission, but also facilitate social distancing and discourage face touching.

As all these questions are being posed, we become increasingly aware of the value of our Mitori project, which brought together a diverse group of enthusiasts who quickly forged a team spirit and learned so much for one another. In a sense 'Mitori' has come to be a boundary object for us. Separated by geography, time zones, professional cultures and social conventions, we came together in what became a most inspiring way. We began and hope to maintain, careful watch on end of life issues in Japan and the UK.

Acknowledgements

We are grateful to Tetsuya Kishimoto, First Secretary (Health, Labour and Welfare) at the Embassy of Japan in the UK for his interest and support for the work and we thank the Economic and Social Research Council, grant number ES/S013865/1 for funding under its UK-Japan Social Science and Humanities Connections scheme, and Sean Nolan at ESRC for his encouragement and advice.

The core members of the Mitori team were: David Clark; Hirobumi Takenouchi; Gitte Koksvik; Yoshinori Takata, Marian Krawczyk, Haruka Hikasa, Chao Fang, Miho Tanaka, Joshua Gallagher, Amy McCreadie and Akiko Nishio.

[1] See: #####
[2] See: https://www.gla.ac.uk/research/az/endoflifestudies/projects/the-mitori-project/ accessed 21 March 2020
[3] See: http://endoflifestudies.academicblogs.co.uk/reflections-on-the-mitori-project-so-far/ accessed 21 March 2020