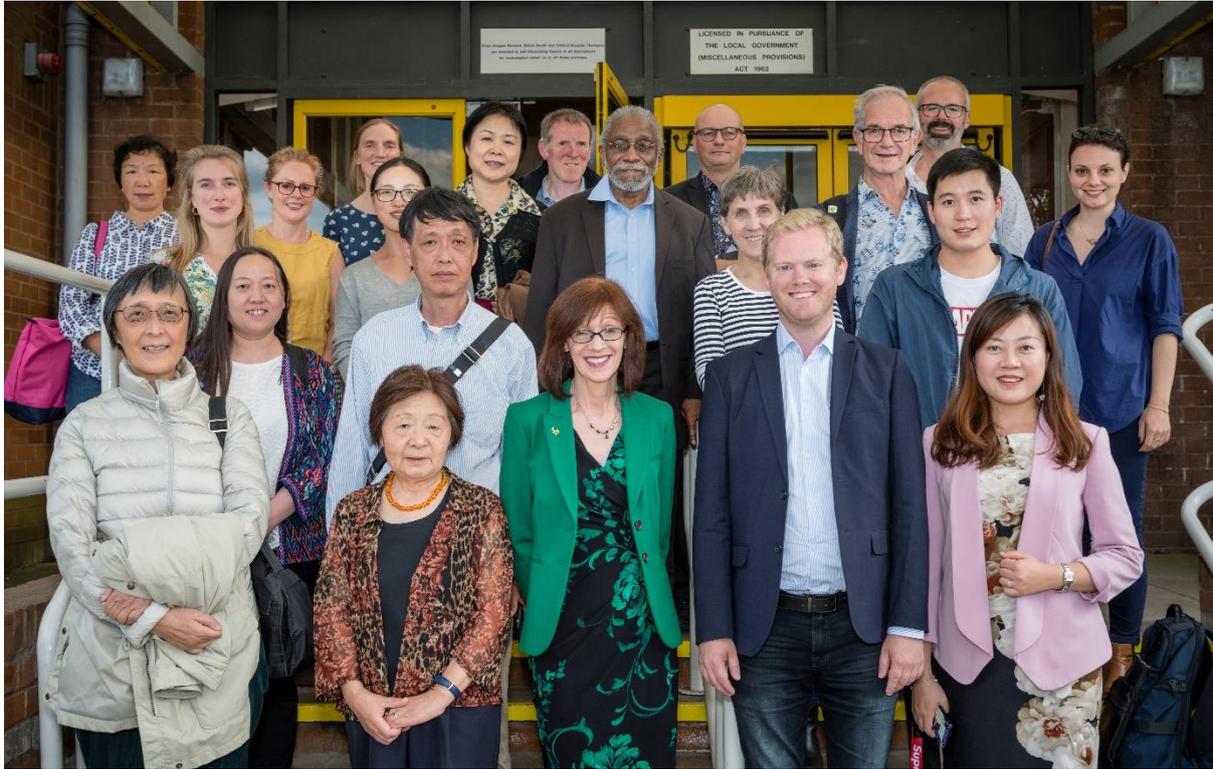


# PROJECT REPORT

## Roles, Responsibilities & The Future Care of Older Adults: A Cross-Cultural Networking Project – Funded by the Wellcome Trust



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## 2. EXECUTIVE SUMMARY

**The original aims of the research proposal were to:**

i) Conduct initial scoping work, and ii) Build a sustainable, international network that enabled the research team to explore the following questions:

- Whose responsibility is it to arrange care for older people? Does this responsibility fall on the older person him/herself; the family or friends; charities; or the State?
- How should these responsibilities be enacted through policy formation, in practice settings across cultures?
- What philosophical underpinnings support the enactment of elder care policy and practice in different cultures?

We utilised a case-study approach adopted across two different national settings – the UK and China. Our intention was to create a specific empirical focus for detailed, cross-cultural analysis which would act as a springboard for the exposition and exploration of a much wider range of varied, international and interdisciplinary approaches to the philosophy, policy and practice of the care of older adults.

### **The Networking Process**

We brought together 15 experts from China, Singapore, Japan, USA, Canada and Europe for a 3-day workshop to share commentaries in response to the 4 case studies (which related to home care and residential care) and to engage in cross-cultural, inter-disciplinary dialogue. The focus was on local understandings and practices of how roles and responsibilities in the care for older adults are being conceptualised in the global context.

#### *The Case Studies & Commentaries*

There was agreement that there were common themes within the case studies, from China and the UK, regarding roles and responsibilities in the care of older adults. The expert commentaries stimulated a wide range of perspectives and discussion topics. Each commentator introduced **questions that require further exploration** (see Section 6 of this report), **for example:**

What are reasonable expectations of family members? Are environmental conditions adequate for ageing societies? Can a person-centred approach be reconciled with public health promotion in mid- and later life? How might competing values be balanced regarding the use of technology in care? How might sibling rivalry be negotiated within a care ethics framework? How might the value of filial piety be extended to include the wider community and society? Is care leave (to care for older adults) an obligation of the State? Who is best placed to respond to the needs of childless older adults? Who should pay for care? How should care-givers be enabled to deliver dignity in care? Is wilful blindness a feature of care systems that result in the needs of older adults being neglected? Should the cost of long-term care be a public or private responsibility? And what does it mean to be owed 'a decent life' in later years?

### *Public Engagement Events*

Collaboration with a London theatre company – Entelechy Arts (see <http://entelechyarts.org/#>) – enabled an immersive theatre experience for project meeting participants and the public, followed by a panel discussion with representation from the arts, politics, medicine and philosophy. (See Section 7 of this report and project press release - <https://www.surrey.ac.uk/news/innovative-meeting-examines-roles-responsibilities-and-future-care-older-people>).

### *The Café Conversation Event*

On Day 2 of the Networking Meeting, the core group of researchers and international participants were joined by older people, carers, local researchers and practitioners. The event involved 3 groups rotating around 3 tables on themes of Policy, Practice & Philosophy (See Section 8 of this Report).

Regarding **Policy**, there was discussion regarding strategic approaches to policy development and the importance of staying close to the lived experience of older adults and their families and to evidence: ‘no numbers without stories, no stories without numbers’. Policy relating to transportation, affordable housing and the development of healthy cities (with sensitivity to cultural differences) was considered critical. There was discussion of the WHO’s ‘Making Fair Choices’, the importance of sustainability and of continuity of care in care transitions. Participants referred to innovative policies in Europe and Canada, for example, that enabled inter-generational living and a prevention-focused approach. The need for a systematic cross-cultural policy analysis was highlighted regarding what enables and inhibits good care and a longer-term values-based approach.

The Café Conversation groups explored many interesting topics relating to **Practice**, for example, the meaning of ‘practice’, inequalities in care provision, challenges in care, moral emotions in care, recognition of a growing problems of loneliness and depression, unpreparedness for uncomfortable discussions relating to ageing and dying and different models of care. There was recognition that care-giving introduces a wide range of ethical issues for care-givers, care-recipients, communities and countries. Discussion focused, for example, on the need for care-givers to have appropriate education and reward for this important work. Justice and activism were considered appropriate considerations in relation to care practices.

The discussion relating to **Philosophy** introduced questions regarding the possibility of a universal approach to thinking about the philosophy and ethics of care of older adults. There was reference to dignity (absolute worth and value) as the starting point and to competing norms regarding what counts as quality and equality in relation to care. Philosophical blind spots were identified as: not knowing what values such as ‘dignity’ requires in practice and what practical constraints can impact on the enactment of values. Other philosophical challenges relate to the understanding of ‘needs’ and to the impact of cultural values on older adults, for example, in differences regarding information-sharing in families in different cultures.

## **Unexpected Discoveries**

We set out to explore questions relating to responsibilities in relation to care for older adults and to understand how these responsibilities are enacted and conceptualised in China and the UK. We had expected indications of cultural differences in policy, practices and philosophical underpinnings. The project revealed these, most significantly, in relation to state provision and the roles and responsibilities of families and communities. The contributions of expert commentators revealed a diverse and rich range of disciplinary and cultural differences in perspectives.

What was unexpected were the similarities amongst the case studies, developed independently from scenarios in China and the UK. Each case study revealed similar ethical challenges for families and each suggested similar expectations regarding gender roles and an appreciation of family responsibilities. What was common to the four case studies were family negotiations regarding roles and experience of moral emotions, such as guilt and shame, during care transitions for older people. Philosophical underpinnings, such as duties and virtues, were implied in the case studies as are intergenerational implications. These are area for further exploration.

The arts, in the form of the Entelechy Theatre Group, stimulated a range of responses from members of the public of all ages and project participants. One said: 'It was so unexpected and was a very powerful message on the lives of elderly people around us and the problems they face [and] how their lives could be enhanced if they could share their concerns with people who have time to listen and advise.' Another said: 'This was a thoroughly authentic experience [...] It was both enjoyable and disconcerting at the same time [...]' (See Section 7 of the report)

## **New Skills, Connections and Insights**

This project enabled participants to engage in, and hone skills in listening to, and engaging with cross-cultural discussions relating to the project theme and broader cultural issues. The PhD students who participated had opportunities to develop skills in summarising wide-ranging small group discussions and distilling key themes for the larger group. Students from the languages unit had opportunities to develop skills in interpreting during group discussions, a visit to a retirement community and during the immersive theatre experience. Connections were made, and relationships developed, across cultures, disciplines and amongst members of the public, professionals and researchers. The development of relationships led to the cross-fertilisation of ideas - particularly in relation to philosophy, policy and practice. The development of question areas will underpin a future research project.

## **Project Outputs**

We have produced four case studies, 13 commentaries on these from international experts, a project report, two editorials and a call for papers on the project theme. We are working on publications relating to the case studies and commentaries.

## **Next Steps**

The project leads, in collaboration with project participants, will develop an application for the January 2020 Wellcome Trust collaborative grant call.

### 3. PROJECT OVERVIEW

#### INTRODUCTION

The population is ageing, and the need for care in later years is growing (World Health Organisation 2018). People aged over 60 comprise 13% of the world population (25% in Europe). There is a projection that people aged 80 and over will triple by 2050 from 137 million in 2017 to 425 million in 2050 (United Nations 2018). New approaches to maintaining ethical care and support frameworks for older adults are emerging around the world. These approaches take many different forms, reflecting background demographic, economic, social and cultural contexts.

Currently, the bioethics discourse around care in old age is limited in both scope and content, with the diversity in approaches being commonly explained in unsophisticated claims about differences between the 'east' vs. the 'west'. What Nie (2011 p.11), a leading figure in cross-cultural bioethics, writes about medical ethics underpins the motivation for our project:

[...] promoting long-term co-existence, continuous dialogue, reciprocal learning and criticism, ongoing negotiation and mutual flourishing, as well as reasonable ways of dealing with dissimilarities and tensions.

Nie writes also that:

[...] the first task of an adequate transcultural bioethics is to expose those stereotypes and stereotypical ways of characterising cultural differences, whether in overt or disguised terms (p.8).

There is a paucity of cross-cultural empirical and philosophical bioethics research that seeks to explore and compare roles and responsibilities relating to elder care.

**Our PRIMARY AIMS** were to:

- (i) Conduct initial scoping work; and
- (ii) Build a sustainable, international network that enables us to explore philosophical underpinnings, policy and practice by engaging with the following initial questions:
  - Whose responsibility is it to arrange care for older people? Does this responsibility fall on the older person him/herself; the family or friends; local communities; charities; or the State?
  - What philosophical underpinnings support the enactment of elder care policy and practice across different cultures and geographical settings?
  - How should elder care responsibilities be enacted through policy formation, and in practice settings, across cultures? For example, should care needs in later life be realised by financial investment, by practical support, by bolstering

existing family and community structures, through regulatory enforcement, or via innovative technological interventions?

The project activities aimed to drill down into the dominant policy, practice and philosophical narratives that have been advanced, in different settings and cultures. We aimed to show, in rich detail, how these narratives shape overarching strategies that are more or less characteristic of different settings. We speculated that such strategies might include: the integration of health and social care services (e.g. UK, Europe and the USA); legal and regulatory reform seeking to enforce and enhance family caregiving responsibilities (e.g. in China and Taiwan); international migration to expand the paid caregiving workforce (e.g. in Singapore, Hong Kong); and expansion of, technology for supporting care and independent living in old age, including the use of robotics and AI (e.g. Japan, South Korea).

## **PROJECT ACTIVITIES**

The project activities undertaken enabled important networking and initial scoping work on the topic of roles and responsibilities in providing care and support for older adults. A core element of the planned activities was the stimulation of cross-cultural and interdisciplinary exchanges and also public engagement.

We adopted a case-study approach developed across two different national settings - the UK and China. These settings provided a specific empirical focus for detailed, cross-cultural analysis and also acted as a springboard for the exposition and exploration of a much wider range of varied, international and interdisciplinary approaches to the philosophy, policy and practice of old age care. We realised the full potential of this approach through two main steps:

### **i) Conceptualising cultures of care**

We developed four case studies, two from England and two from China. One case study in each country focused on the domestic setting and the other focused on an institutional setting (a care home or nursing home). (See **Section 5**). To support the case study development work, we organised a two-day meeting between Chinese and UK collaborators in Xiamen, China.

### **ii) Instigating cross-cultural analysis and network building**

In Month 6 of the project, we convened a major three-day international meeting in the UK (see **Section 4** for programme and participants). This followed circulation of the case studies to experts in 11 countries. Each expert participant submitted 1000-word commentaries (see **Section 6**) and these were discussed at the three-day event. The case studies and commentaries stimulated extensive dialogue and analysis about different strategies for old age care. In so doing, we illustrated the potential value of adopting a cross-cultural and comparative approach to bioethical inquiry, and created a network of like-minded scholars, policy-makers and practitioners that are optimally placed to continue to work together beyond the life of the networking grant.

#### 4. PROJECT PROGRAMME AND PARTICIPANTS

##### DAY 1 – 20<sup>th</sup> June 2019

8.20am	<b>Leave Mandolay Hotel</b> ( <a href="https://www.guildford.com/">https://www.guildford.com/</a> ) <b>&amp; Walk to Duke of Kent Building, University of Surrey</b>
9am	<b>Welcome &amp; Introductions</b> Ann Gallagher, Mikey Dunn & Vince Emery (DVC International)
9.30 – 11am  10 mins to present & 10 mins Q & A each	<b>Commentaries (1)</b> (i) Vikki Entwistle – Singapore - <a href="https://cbme.nus.edu.sg/people/all-staff/prof-vikki-ann-entwistle">https://cbme.nus.edu.sg/people/all-staff/prof-vikki-ann-entwistle</a> (ii) Nancy Berlinger – USA - <a href="https://www.thehastingscenter.org/team/nancy-berlinger-ph-d/">https://www.thehastingscenter.org/team/nancy-berlinger-ph-d/</a> (iii) Jean Woo – Hong Kong - <a href="http://www.mect.cuhk.edu.hk/people/jeanwoo.html">http://www.mect.cuhk.edu.hk/people/jeanwoo.html</a> (iv) Tom Walker – Northern Ireland - <a href="https://www.qub.ac.uk/schools/happ/Research/find-a-PhD-supervisor/Dr-Tom-Walker/">https://www.qub.ac.uk/schools/happ/Research/find-a-PhD-supervisor/Dr-Tom-Walker/</a>
11am	<b>Tea/Coffee</b>
11.30 – 1pm  10 mins to present & 10 mins Q & A each	<b>Commentaries (2)</b> (v) Rueben Warren – USA – <a href="https://www.tuskegee.edu/about-us/centers-of-excellence/bioethics-center/welcome-from-the-director">https://www.tuskegee.edu/about-us/centers-of-excellence/bioethics-center/welcome-from-the-director</a> (vi) Jing- Bao Nie - China/New Zealand – <a href="https://www.otago.ac.nz/bioethics/people/academic/profile/?id=665">https://www.otago.ac.nz/bioethics/people/academic/profile/?id=665</a> presented by Xiang Zou <a href="https://www.otago.ac.nz/bioethics/people/academic/profile/?id=665">https://www.otago.ac.nz/bioethics/people/academic/profile/?id=665</a> (vii) Emiko Konishi - Japan - <a href="https://www.researchgate.net/profile/Emiko_Konishi2">https://www.researchgate.net/profile/Emiko_Konishi2</a>
1 to 2pm	<b>Lunch</b>
2 – 3.30pm  10 mins to present & 10 mins Q & A each	<b>Commentaries (3)</b> (viii) Hsiung Ping-Chen – Hong Kong - <a href="http://www.hkhumanities.hk/view/fellows-inside.php?id=18">http://www.hkhumanities.hk/view/fellows-inside.php?id=18</a> (ix) Alison Armstrong – UK - <a href="https://whiteleyvillage.org.uk/whiteley-foundation/">https://whiteleyvillage.org.uk/whiteley-foundation/</a> (x) Dagfinn Naden – Norway – <a href="https://www.oslomet.no/om/ansatt/dagfinn/">https://www.oslomet.no/om/ansatt/dagfinn/</a> (xi) Ross Upshur – Canada – <a href="http://www.dlsph.utoronto.ca/faculty-profile/upshur-ross-e-g/">http://www.dlsph.utoronto.ca/faculty-profile/upshur-ross-e-g/</a>
3.30 – 4.30pm  10 mins to present & general reflection	<b>Commentaries (4)</b> (xii) Michael Gusmano – USA – <a href="https://www.thehastingscenter.org/team/michael-k-gusmano-ph-d/">https://www.thehastingscenter.org/team/michael-k-gusmano-ph-d/</a> [Presented by Mikey Dunn] (xiii) Dave Archard – UK – <a href="https://pure.qub.ac.uk/portal/en/persons/dave-archard(2f61a084-c14e-4f7b-bb66-d695fe5966e3).html">https://pure.qub.ac.uk/portal/en/persons/dave-archard(2f61a084-c14e-4f7b-bb66-d695fe5966e3).html</a> [Presented by Ann Gallagher]

<b>on the day</b>	
<b>4.30-5pm</b>	<b>Closing comments</b> - Yonghui Ma, Ya Fang and Zhaoxu Xu, Xiamen University
<b>7.30pm</b>	<b>Dinner @ The Keep Pub</b> ( <a href="https://the-keep-pub.business.site/">https://the-keep-pub.business.site/</a> )

### DAY 2 – 21<sup>st</sup> June 2019

**Room 16, Ground Floor, Kate Granger Building, School of Health Sciences, University of Surrey**

<b>8.30am</b>	Leave Mandolay Hotel by bus
<b>9.30am to 12.30pm</b>  <b>45 minutes each round, with short break in between</b>	Conversation Café X 3 iterations for wider consultation (see <a href="http://www.conversationcafe.org/the-complete-hosting-manual/">http://www.conversationcafe.org/the-complete-hosting-manual/</a> )  Table 1 – Policy – Chaired by Nancy Berlinger Table 2 – Practice – Chaired by Alison Armstrong Table 3 – Philosophy – Chaired by Tom Walker
<b>12.30pm</b>	Bus to Whiteley Village Retirement Community – Lunch, Tour and Meeting with Residents and Staff ( <a href="https://whiteleyvillage.org.uk/">https://whiteleyvillage.org.uk/</a> )
<b>4.30pm</b>	Return to University of Surrey by bus
<b>5.30 to 7.30pm</b>	Public engagement event: participatory theatre performance & panel discussion in PATS studio, University of Surrey on the topic “Who is Responsible for the Care of Isolated Elders?” See <a href="https://www.surrey.ac.uk/events/20190621-who-responsible-care-isolated-elders">https://www.surrey.ac.uk/events/20190621-who-responsible-care-isolated-elders</a> Tickets booked for international experts.

### DAY 3 – 22<sup>nd</sup> June 2019

**Room 14, 2<sup>nd</sup> Floor, Duke of Kent Building, University of Surrey**

<b>9am</b>	Leave Mandolay Hotel ( <a href="https://www.guildford.com/">https://www.guildford.com/</a> ) & Walk to Duke of Kent Building, University of Surrey
<b>9.30 to 10.30am</b>	1) <b>What have we learnt?</b> Key ideas concerning policy, practice and philosophy? How do these ideas relate to understanding roles and responsibilities in caring for older adults?
<b>10.30 to 11am</b>	Coffee/tea
<b>11am to 12md</b>	2) <b>Clarifying next steps.</b> How do we take this work forward in terms of future research and network building activities?
<b>12md</b>	Closing comments – Ann & Mikey
<b>12.30pm</b>	Meeting close

Participants – 20 <sup>th</sup> to 22 <sup>nd</sup> June	Additional attendees at Café Conversation event on 21 <sup>st</sup> June
<p><b>Research team</b></p> <p>Ann Gallagher  Mikey Dunn  Yonghui Ma  Ya Fang  Zhaoxu Xu</p>	<p>Alison Bright  Helen Teresa Edwards  Christopher Herbert  Lucas Hawkes-Frost  Jane Leng  Caroline Nicholson</p>
<p><b>International Experts</b></p> <p>Vikki Entwistle  Nancy Berlinger  Jean Woo  Tom Walker  Rueben Warren  Emiko Konishi  Ian Christie  Hsiung Ping-Chen  Alison Armstrong  Dagfinn Naden  Ross Upshur  *Jing- Bao Nie  *Michael Gusmano  *Dave Archard</p> <p>* <b>Unable to attend</b> - Commentaries presented by Xiang Zou, Mikey &amp; Ann</p>	<p><b>UK Focus Group Participants</b></p> <p>Geoffrey Hunt  Matthew Kapulka  Alison Bright  Helen Teresa Edwards  Christopher Herbert  Jane Leng  Olivia Luijnenburg</p>
<p><b>PhD Students</b></p> <p>Olivia Luijnenburg (Surrey)  Mira Schneiders (Oxford)  Liangwen Zhan (Xiamen)</p>	

## 5. CASE STUDIES

### CASE STUDY 1 - HOME CARE - UK

Harry and Alice Jones have been happily married for 45 years and live together in a small terraced house in the town of Woking that they have rented for the last 15 years. The couple first met whilst working together at Marks and Spencer as teenagers – Harry in the stockroom and Alice as a sales assistant. They didn't save much money over the course of their working lives and are reliant on their state pensions. Now aged 78 and 76 respectively, Harry and Alice have two children and five grandchildren. Their daughter, Hannah, lives in a village locally. Their son, James, has recently moved to Edinburgh with his wife, Molly, and their 3 children in order to be closer to his wife's family and to their youngest son, Luke, who has recently been diagnosed with schizophrenia.

Eighteen months ago, Harry was diagnosed with the early stages of dementia. He had been struggling to remember the names of his grandchildren and started to forget which house he lived in when he went down to the shops to buy the morning paper. The diagnosis came as a huge shock to the entire family, who had never planned for the future. Hannah immediately began to regularly take time off from her job in London to visit her parents. A neighbour, Joan, keeps keys to the Jones' home and checks in on them from time to time. For the next year, Harry's difficulties with his memory gradually increased and he became increasingly reliant on Alice for support around the home – helping him to get dressed and with eating and drinking.

As time passed, Alice found it increasingly difficult to look after Harry. She had developed back pain as she physically assisted him to walk around the home. After struggling to find any clear information online about the additional support options available, her neighbour Joan recommends that she contacts Surrey Council to arrange a needs assessment for Harry and that she applies for Carer's Allowance: a small government subsidy for those with low incomes who undertake caring for another person. The outcome of the needs assessment saw Harry receiving publicly funded support twice a day from a care assistant: for 30 minutes in the morning to help him get ready for the day and down the stairs, and for 45 minutes in the evening to get him upstairs, bathed and ready for bed. Alice did not find this arrangement easy. She struggled with having a stranger coming into their house. As she put it:

Every time I hear the knock on the door, I experience this enormous feeling of shame. He needs me so badly and I just feel like I've failed him. And she strides straight into his bedroom – *our bedroom* – without even as much as a hello. She has no idea what he likes to wear or what time he actually wants to get out of bed. I can't bear it.

The care visits rarely go smoothly; Harry gets agitated when different people, employed by the Council, turn up on different days. He frequently shouts out:

“Who are you? Why are you fussing? Go away. I can look after myself.”

The timings of the visits are also causing difficulties. Harry has always been late to bed, but the Council's schedule is fixed to the early evening due to staff shortages and shift patterns. Alice frequently gets upset when she hears Harry upstairs, lying in bed alone, unable to sleep, and crying out for her repeatedly.

One month later, Alice and Harry receive a letter from Surrey Council indicating that Harry's needs are subject to an annual reassessment. Despite knowing from her local carers' group that funding cuts to local adult care services have led to people having services withdrawn, Alice is still shocked that the outcome of this new assessment is the withdrawal of care in the morning. This was apparently on the grounds that Harry was judged to be mobile enough to get downstairs without assistance. Hannah visits her mother and finds Alice in tears in the living room. Comforting her, Hannah asks what she can do to help. Alice replies:

Everything's turned upside down. This last year, I've become his banker, his cleaner, his gardener, his cook, his carer, and now they want me to magically transport him around the house too. How can I possibly get him downstairs on my own? And what's the point anyway? We can't leave the house. We just sit in the living room all day watching TV until I can sneak off to the shops to buy our dinner when he's not looking. I'm just worrying about him all the time.

Hannah suggests that she and James could play a greater role in helping her mother and the family arrange to get together to work out how best to care for their father moving forward. Hannah presents a number of ideas. She wonders if a new volunteer scheme in the local area could help out with some of the care activities that Alice is struggling with. She also suggests that she could move back in to her parents' home during the week and commute into London – getting her father out of bed, helping him to the toilet, all before she goes to work. Alice is not convinced:

You've got your own life to lead, and your own children to take care of. That's too much to ask. And we can't just rely on local students or volunteers to help out at the weekend. Your dad needs proper care, not just a helping hand.

James, who has only been in infrequent contact with his mother over the last 6 months, says that he's happy to help financially. He explains that he doesn't feel that he can do any more himself because of the time he needs to spend looking after his son's mental health needs. Instead, he suggests that he pays for a private care assistant to replace the visit that has been cut and that he buys his father an 'Alexa' that would keep him occupied during the day. Hannah snaps back:

That's your solution to everything isn't it – throwing money at the problem! Why can't you put your father first when your family needs your help?

Alice tries to calm things down and agrees that buying in some extra assistance could help. She's also aware of a new neighbourhood scheme established by Age UK called 'Communal Cooking', where caregivers take responsibility to cook

numerous evening meals for older people and their families on different days in order to share this burden. In response, Hannah says:

These ideas are fine, Mum, but they're just sticking plasters really. We might be able to hold things together for a few more weeks, but your back's getting worse, Dad's getting more agitated by the day, and James's money will run out sooner or later. What are we going to do when that happens?

### **CASE STUDY 2 - HOME CARE – CHINA**

Wu Haichuan and Huang Ning are a loving couple who have been married for more than 60 years, They live in Xiamen, a coastal city in southeastern China. Wu Haichuan is 94 years old and Huang Ning is 89 years old. They have four children: a son Wu Xin and three daughters, Wu Ping, Wu Zhen and Wu Qian.

Mr Wu Haichuan is very cheerful. He had worked at sea for a long time and is physically fit. However, he has hearing difficulties and relies on writing or gestures to communicate with people. Mr. Wu attaches great importance to exercise and routine. He gets up at 5 o'clock every morning, drinks a large cup of boiling water and then does massage for one hour. After that he walks for 2 hours, goes home for breakfast and reads the newspaper. Mr. Wu is a devout Buddhist and a calligraphy enthusiast. After taking a nap every afternoon, he will drink tea in the study while copying the Buddhist scriptures. His work was sent to the temple by one of his daughters. Mrs Huang Ning likes to play mahjong with her neighbours. In recent years, her physical condition has deteriorated. Since some friends now live in the nursing home and others have died, the number of players is not enough for mahjong playing. Now her only entertainment is watching TV.

The four children have a deep feeling for their parents' hardships in their early years and hope that their parents will be able to enjoy their old age. They visit their parents as often as they can and help them cook and clean. Half a year ago, the peaceful life of the old couple was disturbed when Mr. Wu was diagnosed with a malignant tumour of the prostate with bone marrow metastasis. He urinated frequently at night and his wife had to assist him. As a result, she was not well rested and became unwell with abdominal pain. The four children had to take turns to stay with their parents at night. Despite treatment with hormones, Mr. Wu 's condition worsened and he became bedbound and incontinent.

One night, Mrs Huang Ning suffered from acute abdominal pain due to gallstones. and was rushed to the hospital for emergency treatment. Their four children were very busy with their family and work commitments. Wu Xin lives an hour's drive from his parents. He has a very stressful job in a university and is worried that he will be unable to complete important research projects. Wu Ping is the eldest daughter of Mr. Wu. She is suffering from coronary heart disease and arthritis. She lives 100 kilometres away from Xiamen. Travelling to and from her parents' home is difficult for her due to her disability. Wu Zhen is the second daughter of Mr. Wu and lives in

Xiamen. She is retired and cares for her ill husband. Wu Qian is the third daughter and is a widow. She lives near her parents and visits often. There was pressure on her to live with her parents, to be their 'small cotton-padded jacket'. However, she has two grandchildren under three years old, and her son and daughter-in-law are at work. Her daughter-in-law's leave to take care of the children is about to expire and Wu Qian feels torn between her duties as a daughter and as a grandmother. Each of the children experience different challenges in responding to their parents' needs.

After Huang Ning was discharged from the hospital, Wu Xin suggested a family meeting to consider different options and to find a solution for the above difficulties. The family considered finding a nursing home for their father, however, they were reluctant to do this as they worried about the standard of care in the nursing home. The second option was to ask the domestic worker to do housework and to take care of their parents. However, most housekeepers are not so professional and it is difficult to find someone who is responsible. After some discussion, the four children decided that they take the main tasks of caring for their parents and the domestic worker would help them.

The four children agreed a division of labour. Wu Xin would be responsible for transporting their parents to the hospital and helping with medication. Wu Ping is good at cooking, so she would be responsible for buying food and cooking for their parents. Wu Qian is more careful, so she is responsible for helping with meals, giving medicine and maintaining their parents' hygiene. Wu Zhen is responsible for helping with laundry and other household chores. In addition, they would hire a nanny who can take responsibility for dealing with Mr. Wu's night care and bringing Mr. Wu outdoors. They agreed to take turns to keep their parents' company 24 hours a day and also to have help from the domestic worker.

After a while, it was agreed that more help was needed and a care company was approached. However, when care-givers recruited came to understand the situation, some turned around and left as they were not willing to do this nursing work because Mr. Wu is so seriously ill or because they are supervised so closely by his son and daughters. Wu Xin visited the nursing management station of a major hospital and finally found a care worker, Zeng Li, who was introduced by a nurse manager. Zeng Li is 65 years old and has been engaged in nursing work for more than ten years. He mainly has experience of working with patients who had strokes. He is physically strong and has been a soldier when he was young. He lives on an island in Zhangzhou City where it takes a 3-hour drive from Xiamen. Due to family commitments, Zeng Li needed to make money. He is not well educated and found it difficult to find a job. He decided to become a care worker. Zeng Li demanded a daily wage of 230 yuan, which is higher than the market price. Mr. Wu's pension is only 4,000 yuan. Zeng Li's monthly salary is nearly 7,000 yuan, which exceeds Mr. Wu's pension of 3,000 yuan. Wu Xin discussed the situation with his three sisters and finally agreed that he will bear half of the expenses and the other half will be borne by the three sisters on average. In fact, Wu Xin had given his mother a living allowance of 1,000 yuan per month before, and the house where his parents lived

was also purchased by him. However, among the four children, his economic conditions are better. Besides, his work is busy, and the time for caring for his parents is less than that of the three sisters. Therefore, he is willing to bear the main cost of nursing care for his father.

After a while, problems arose as Zeng Li sometimes slept very deeply and didn't hear Mr Wu when he called for water or help with toileting. When he was a care worker in the hospital, he could talk and laugh with other care workers and now he very lonely. The family became unhappy with the care provided, however, they felt they had no choice but to agree to Zeng Li's requests for a higher salary and more rest period. On one occasion, following Mr Wu attempting to pull out his catheter, Zeng Li tied Mr. Wu's hands to the bed. The family eventually felt they had no option but to dismiss Zeng Li. They then had to resume providing care for their parents in addition to their other family and work commitments.

### **CASE STUDY 3 - RESIDENTIAL CARE – UK**

Greta Smith is 85 years old. She was born in Italy and had a very active early life. She studied history and physical education and became a primary school teacher. Greta met and married Arthur and they had 3 children: Maria, David and Daniel. David moved to the north of England and married Jane. Eldest child, Maria, lives in the same Surrey town as her parents and is married to Dennis. They had two children who are now in their early thirties. Maria is looking forward to the birth of her first grandchild in 2019. She plans to help out with the grandchild one or two days a week so her daughter can go back to work. Greta's favourite son, Daniel, moved to Italy and lives there with his partner, Giuseppe. Maria said she remembers 'as a child promising my parents that I would never let mum go into "a home"'.

Greta was diagnosed with rheumatoid arthritis in her forties and, as the years went on, her physical disability increased. Her husband Arthur helped her with many of the things she struggled with. The couple very much enjoyed living near Maria, Dennis and seeing their two grandchildren. Arthur developed cancer and died in a hospice five years ago. The full extent of Greta's care needs only became apparent when Arthur was no longer there to assist her. As their two children had moved out, Maria and Dennis agreed that Greta should come and live with them. Maria became aware that her brothers had 'chosen not to be involved' in their mother's care. She wondered if 'they just didn't care enough'.

As Greta's care needs increased, Maria gave up her job to be in a better position to assist her mother. Maria said: 'I suddenly realised that mum was slowly having to cope with so many losses in her life and that I should be there for her.' However, over the next year Greta's ability to care for herself declined. Maria said that:

[...] the crisis point came when my mother fell and broke her shoulder. She was in hospital and rehabilitation for a few weeks. I began to see that the strain of looking after her would be impossible. She was unable to use the

toilet unaccompanied, she needed to go frequently during the night and was too unsteady on her feet to be alone. Mum very much wanted to come home, but I couldn't see how this was possible. With a heavy heart, I found a care home less than a mile away, and we agreed that mum would go there when she came out of rehab, to see how much she would improve.

To find a good care home, Maria went to the Care Quality Commission (CCQ) website and checked out the ratings of homes in their areas in the 'find a care home' section. The CQC regulates health and social care services in the UK. Maria said:

The care home was good, but mum didn't like it and made no effort to mix with the other residents. I visited daily and remember walking home from there in tears very often in the first few weeks. I felt huge guilt at the situation and in breaking my childhood promise.

The care home Greta moved to was in a quiet residential area. Greta had a ground floor bedroom, bathroom and a patio so she could tend some plants in pots. She had always enjoyed gardening, bird-watching and sitting in the sunshine. Maria began to get involved in the 'friends and family group' at the home and helped out with the activities. There were regular events to join in with, for example, film afternoons and bingo. Maria was also involved in a discussion about cameras in the care home. There was discussion of benefits for residents and staff of technology. Maria reported a positive example which helped her mother communicate with her and Dennis when they were on holiday:

[...] Mum had her iPad and a family friend helped her to set it up so we could talk with her when we had a short holiday in Spain.

Over time, Greta became resigned to the care home and began taking meals in the dining room. She had conversations with staff about her future care and treatment and her wishes were documented in a care plan. Greta began to develop a friendship with Jack, a fellow resident, and they found that they shared some common interests. When Maria returned to the care home after the holiday, she found Greta holding hands with Jack in the day room. Greta and Jack began to spend more and more time together and staff began to express concerns, amongst themselves, about the relationship. They worried that Jack was 'very affectionate' and would, at times, close Greta's bedroom door when they were together.

Greta seemed happier although, from time to time, she was forgetful and would sometimes refer to Jack as 'Arthur'. Maria was pleased that her mother had 'a companion' in the care home. Six months after Greta came to the care home, her son David visited. He complained to the staff about many aspects of his mother's care. He particularly expressed concern about the relationship with Jack and about the cost of her care. The home manager had a meeting with staff who shared the view that David, who had previously been distant, was trying to 'micro-manage' his

mother's care. They had come across this previously with other residents' family members:

[...] but micromanaging someone, saying 'my mum needs to go to bed at this time and, you know, she likes a blue cardigan on a Wednesday and a lavender one on a Friday.

Beata, a care-giver from Poland, saw the positive aspects of family involvement:

The family are the keepers of the memories of that person [...] By the time they go into residential care a lot of these memories are gone, so I think the families are sometimes saying 'well, he likes tea, he likes coffee', they're trying to preserve what they feel their relative wants because that's their memories of them and I think they don't want that tarnished.

David visited his sister, Maria, and said he was unhappy with decisions made about his mother's care. He asked about the cost of her care and seemed shocked to learn that it is £1200 per week as Greta had over £23,250 savings. David said he planned to explore other options near his home, using a 'care sourcer' website, which would provide specialist care with a view to moving Greta. Maria phoned Daniel, asking him to come home' to help out'. Daniel said he was at a critical point with a project and couldn't get away. He advised that his mother should stay where she is as 'she is happy there.'

#### **CASE STUDY 4 - RESIDENTIAL CARE – CHINA**

Wang Yuying is 86 years old. She lives in a rural area Xiamen and finished middle school education. Before her retirement, she was a factory worker. Mrs. Wang met and married Chen Hua and they had 4 children (three sons and one daughter) together: Chen Jia, Chen Yi, Chen Bing, and Chen Ning. Chen Jia and Chen Yi has one child each, who were brought up by Mrs. Wang. Chen Bing studied and migrated later in the United States. When Mrs. Wang's grandchildren grew up, they moved to the big cities of Shanghai and Guangzhou, China. Chen Ning, her only unmarried and youngest daughter, still lives near with her in Xiamen.

After Mrs. Wang's retirement, she spent most of her time taking care of her two grandchildren, Chen Qi and Chen Hui. She went to the market to buy food, regardless of the weather and cooked for her family every morning. During this time, Mrs. Wang was still able to take good care of her husband and her grandchildren. Mrs. Wang owned farmland, not far from her home, and she grew and harvested vegetables and potatoes. After her husband died of lung cancer in 2010, Mrs. Wang's physical health deteriorated. She had difficulty walking because of muscular atrophy and myasthenia. This prevented her from working in the fields and even going to the market for food.

As a result, Chen Ning, as her youngest daughter, assumed responsibility for taking care of her. As a waitress in a local restaurant, she often visited her mother after

work and did lots of chores, like cooking, washing clothes and so on. Chen Ning said that:

It was not easy for a mom to bring us up and my brothers are not around her. Thus, I need to take more responsibility for caring my mother. Despite I'm busy with my work, I can't let relatives and neighbours laugh at my mother because there is nobody taking care of her.

Mrs. Wang realized that her daughter was having a hard time taking care of her and she decided to go to a residential care home for long-term care. She said:

Now, I feel terribly sorry for my little daughter. The burden of caring for us all overwhelmed her. Although my sons invited me to stay with them, I refused because I didn't want to be a burden and I'm too old to adapt the new environment in the city.

Mrs. Wang heard from an old friend that the care service of Lotus Care Nursing Hospital in Xiamen City, not far from home, was good. This private residential care home is located next to the hospital, therefore, it is very convenient to see a doctor if necessary. The environment is beautiful and well-suited for the needs of elders. There is a large balcony from which one can see many lovely flowers and plants in the garden. Moreover, the staff are careful and friendly and ensure there is good service quality and a nice atmosphere. Mrs. Wang asked her daughter to take her to this care service centre and after seeing the facility, she decided to stay there. Her children, especially the oldest one, were strongly against her plan at first. However, when they found out that Mrs. Wang was well cared for in the institution, their views have changed. Now, her children take turns to visit her in the care home every week.

Mrs. Wang's nursing expenses were assessed by the care agency and were identified as a mild disability. Finally, her nursing costs were set at 6,000 yuan (RMB) per month. It consists of 2400-yuan for basic nursing, 600-yuan for food and 3000-yuan for bed in a double room. Half of the expenses are coming from Mrs. Wang's pension and the remaining is shouldered by her children. The son who works abroad said 'I am far away from home and can't visit my mother frequently so paying a greater part of her expenses is the best I can do.'

In the early process of being taken care of, Mrs. Wang became sleepless and anxious because she had a hard time adapting to the new environment. The experienced Head Nurse, Mrs. Zheng, communicated with Mrs. Wang's children to find out more detailed information. She learned that Mrs. Wang liked watching TV and eating fruit. Having heard of this, Mrs. Zheng took the initiative to install a TV for the old lady. She made it possible for Mrs. Wang to watch movies and she brought some fruits for her. Mrs. Zheng also helped Mrs. Wang to communicate with her grandchildren and her children using an app called WeChat. The head nurse was able to encourage Mrs. Wang's children to visit her more often. After all of this, Mrs. Wang felt a lot better in the care home. The head nurse said:

Mrs. Wang and other older people in the home require not only physical care and medical treatment but also spiritual care, especially companionship and filial piety.

Two years ago, Mrs. Wang was diagnosed with high blood pressure. Mrs. Zheng informed her family first and then told Mrs. Wang about her condition. From morning to evening, the head nurse arranged for the nursing staff to help her take the medicine as prescribed and to check her blood pressure three times per week. They conducted a physical examination every half year. In addition, the head nurse also arranged for social workers, most of whom are volunteers in the community, to exercise and to carry out rehabilitation training for her leg muscles.

Mrs. Wang had a roommate, Mrs. Liu, who suffered from cognitive impairment. This condition of Mrs. Liu has affected Mrs. Wang's sleeping quality at night. After a discussion with Mrs. Liu's families, she was transferred to a specialized hospital for dementia. Shortly after that, a specialized care sector for dementia was established in the institute. Mrs. Zheng said:

We communicate with the family members in advance and transfer elders to the proper sites for treatment. Psychological and social treatments should always be the priority, while the physical restrictions and medication should be handled moderately.

Unfortunately, Mrs. Wang fell while she was outside a year ago and after that, she was unable to walk normally without assistive devices, like a walking stick. However, she often forgot to use it, which increased her risk of falling again. The head nurse encouraged Mrs. Wang to use the assistive devices including smart anti-fall equipment. A proposal to install cameras in public areas generated a heated discussion amongst staff members and the families of elders.

## 6. COMMENTARIES

### Introduction

The 13 commentaries from international experts were submitted in advance of the 3 day networking event. The experts were invited to write approximately 1000 words in response to the 4 case studies and to present these for discussion during on the first day of the meeting.

The commentaries provided are wide-ranging and insightful responses that focus on roles, responsibilities and philosophy, policy, practice from different disciplinary perspectives. There is a good deal of synergy and commonality amongst the responses and also an abundance of rich and different disciplinary insights relating to philosophy, policy and practice, for example:

What **philosophical or ethical underpinnings** are the best fit for this topic area? Should we draw on rights, duties/obligations, rights, care ethics and/or on values such as dignity, solidarity and/or filial piety? How might inter-generational justice and care be understood?

What **policies** should be in place to support ethical care of older adults within and across cultures? Should, for example, filial piety be enforced by governments? How should care be funded?

What are the ethical aspects of care **practices** in response to the needs of older adults? Why need this fall to women and people from minority groups in particular? And how are the moral emotions of older adults and family members to be negotiated? All three areas – philosophy, policy and practice -are inter-related and there there is need for a more thoughtful and sustainable integration.

### 6.2 Critical questions suggested in Commentaries

These illuminated further the research theme of *Roles, Responsibilities and the Future Care of Older Adults*. A wide range of questions were suggested by international experts and some of these are outlined below:

- What is it reasonable to expect of family members – and others – in relation to the care of older adults?
- What is it fair to expect from individual family members regarding the care of older adults? And
- What is the source and nature of people's obligations in the context of the care of older adults? (Vikki Entwistle)
- How should care needs be anticipated, provided, financed and assessed?
- Can environmental changes in the home accommodate the changing needs of the older adults in the cases?
- Is the community housing stock being designed and built for an ageing society, mindful that the home is the primary site of care? (Nancy Berlinger)

- Might there be a U-shaped relationship between positive attitudes to older adults and economic development?
- Are there sufficient mechanisms in place to detect the unmet needs of older adults?
- Can a person-centred approach be reconciled with public health promotion in mid- and later life? (Jean Woo)
- How might competing values – for example, safety versus privacy - be balanced regarding the use of technology such as cameras in care?
- Why were the voices of older adults not central to decision-making in the case studies?
- What are the responsibilities of the wider community, particularly for older people who are childless? (Tom Walker)
- How should siblings' contributions to promote the best interests of their parents be synergized?
- How sibling rivalry to be negotiated within a care ethics framework?
- What is the role of public health in later life, for example, relating to dementia, particularly in relation to the needs of diverse populations? (Rueben Warren)
- How is the wisdom of indigenous cultures, regarding the care of older adults, to be understood and operationalized?
- How can the value of filial piety (xiao) be extended to include the wider community and society?
- Is it agreed that the state has a duty to develop the favourable social, institutional, economic and cultural environments in which people are able to care for older adults and practice the cardinal virtue of filial piety? (Jing-Bao Nie)
- How favourably do policies relating to longer term care and community assistance compare across cultures?
- Is 'care leave' (to care for older adults) policy an ethical obligation of states?
- How is 'family first' (as in some cultures) to be reconciled with 'older person first'? (Emiko Konishi)
- What might we learn from 18<sup>th</sup> century Chinese literature regarding advice for ageing?
- How does early Chinese writing relate filial piety to the character of a son?
- What ethical imperatives were expressed in early Chinese writing regarding the ways children were advised to serve their parents? (Hsiung Ping-Chen)
- Who is best placed to respond to the care needs of older adults who are childless?

- Who should pay for care?
- How can care and support staff be paid what they deserve? (Alison Armstrong)
- Could a 'Dignity Guarantee' regulation (as in Norway) improve the care of older adults internationally?
- How should care-givers be enabled to deliver dignity in care?
- What responses are appropriate when older adults are humiliated by organisations or individuals? (Dagfinn Naden)
- Why have the demographics of the morbidity transition of older adults not been better anticipated?
- Why are people so ill-prepared when the health and well-being of an older adult deteriorates, resulting in a care crisis, with inadequate policies and practice responses?
- Is willful blindness a feature of care systems resulting in the needs of families and isolated elders being neglected? (Ross Upshur)
- What is the rationale for using social insurance principles to finance pensions and health care?
- Why do we use different principles to finance social and health care?
- How are the burdens of care-giving, particularly of women, to be negotiated? (Michael Gusmano)
- Is everyone owed a decent life?
- Who should discharge the duty of care for older adults?
- What are the reasons for, extent of and form of care that people are obligated to provide to older adults? (Dave Archard)

**The commentaries that follow, in order of presentation, were submitted in advance of the 3 day networking event and shared and discussed on day 1**

## **EXPERT COMMENTARIES**

### **Vikki Entwistle**

Vikki Entwistle is Professor and Director of the Centre for Biomedical Ethics at the National University of Singapore. She has over 20 years' experience of collaborative, interdisciplinary studies of health care quality and ethics, with a particular interest in 'person-centred care' and associated shifts in patients' and professionals' roles and responsibilities.

### **Commentary**

#### **Fair shares in caring? The salience of multiple considerations and the inevitable contestability of assessments**

In each of these cases, as we consider how and how well the care needs of particular older adults are met, we are introduced to a number of people who (might) contribute to their care, and questions quickly arise about what it is reasonable to expect of each of them.

Sometimes the older adults' care needs can be well met via arrangements that everyone involved can agree are broadly fair. But as the older adults' needs for care increase and/or as the situations of those providing care change, arrangements must shift, and disputes about fairness can emerge. As the interaction between Hannah and her brother James in the case of Mr and Mrs Jones illustrates, accusations of a lack of care are sometimes levelled when one person thinks another is not taking their fair share of responsibility. When people are struggling to meet care needs adequately, disagreements about what is fair can worsen already difficult situations.

For the challenging, multifaceted and dynamic kinds of situation represented by these contemporary cases of caring for older adults in ageing societies, there is no simple and clearly good way of adding up and sharing out care needs and responsibilities for meeting them, and no agreed formula for calculating the fairness of particular care arrangements. This commentary aims briefly to outline some key considerations that illustrate and help to explain why the assessment of fairness in the sharing of caring responsibilities is so challenging. It focuses on three clusters of issues.

First, older adults can have plural care needs that can be met in plural ways. These different needs and contributions are not all commensurable, and their importance can be contested. Mrs Zheng, the experienced nurse in Mrs Wang's case, emphasized that older adults need spiritual as well as physical care. Other kinds of needs can be identified too, and people will not always agree which of these are relevant, nor how they should be met – as illustrated by people's different perspectives on companionship and favourite blue cardigans in Mrs Smith's case.

The diversity of ways of contributing to plural care needs was highlighted by Joan Tronto, a key author on the ethics of care, who suggested that, at the most general level, caring could be viewed

“as a species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web”.<sup>1</sup>

Tronto subsequently identified four interconnected aspects of care: caring about (recognising a need for care); taking care of (taking some responsibility to help address it, perhaps by providing financial assistance); care-giving (directly meeting a care need – usually while in close proximity); and care receiving (responding and recognising response to care – including considering how well need has been met).<sup>2</sup> All of these aspects of care are evident in the cases considered, and there are several examples of divisions of labour across as well as between them. But for the purpose of assessing the fairness of these divisions, the ‘sizes’ of different types of care contribution are not readily comparable, the impact of any particular contribution can often not be identified in isolation from others, and the significance of the meeting of particular care needs may look different from different perspectives, including those of the older adult(s) being cared for.

Second, when we turn our focus to the people who could and perhaps should be contributing to an older adult’s care, questions about what it is fair to expect of them can require consideration of both (a) what they are able to do (we do not hold people responsible for not doing what they cannot) and (b) why and how they might be regarded as obligated to care. This is challenging because a person’s capacity and obligation both depend in complex and contested ways on their personal and social circumstances, including their positions within overlapping networks of relationships.

The cases illustrate, for example, how a family member’s capacity or scope to engage in particular aspects of caring for an older adult can be shaped by geographical proximity (which makes direct care-giving easier), financial resources (those with more money are usually better able to ‘take care of’ by buying services), personal needs and other obligations (for example, health issues, needs to work, employers’ demands and commitments to other family members reduce availability to help). Technology can sometimes enhance capacity to contribute (in Mrs Wang’s case, communication technology helped distant family members keep in touch, and it could plausibly have enabled more remote family members in other cases to recognise an older adult’s changing needs for care), but it still does not equalise people’s abilities to contribute.

Ideas about the source and nature of people’s obligations, including to care for older adults, vary to some extent both across and within countries and cultures. Family ties and personal promises are widely recognized as salient, but quite reasonable people can infer quite different implications from them, and other things can also shape duties or responsibilities. Also, because the fulfilment of one obligation can reduce a person’s scope to fulfil other obligations (for example by requiring them to be in a particular place, at particular times, and to use limited personal resources), diverging assessments of the relative importance of obligations can generate diverging assessments of capacity to contribute to the care of a particular older adult.

Third, but related to the two previous clusters of issues, older adults can be – and may need to be supported as – providers as well as recipients of care, and not only within their spousal relationships. An older adult whose care needs are the primary focus of attention may themselves want and in some ways be (en)able(d) to take some responsibility for their own care arrangements as well as to reciprocate by caring somehow even as they receive care. Alice Jones’ intervention when Hannah snapped her accusation at James was arguably an act of caring about and for their relationships while they were all trying to work out ways of caring for Harry and herself. Mrs Wang was able to make her own decision to move into a residential care home to avoid burdening her children. She needed her children’s support to enact this decision, and they gave this despite preferring other options for her care, but they might have done otherwise. Questions about whether and how it is fair to enable and expect older adults to influence their own care and contribute to the care of others need to feature in the complex of considerations about fairness of care provision. Like the other clusters of issues, they are open to contestation.

## References

1. Tronto J. *Moral boundaries: a political argument for an ethic of care*. Routledge, New York: 1993. p103
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## Nancy Berlinger

### PhD, Research Scholar, The Hastings Center

Nancy Berlinger is a Hastings Center research scholar who studies ethical challenges in population aging; decision-making and care concerning serious illness; and safety and harm in health systems, including their role in health care access and social integration for migrants. She co-directs a new Hastings Center project on [“Dementia and the Ethics of Choosing When to Die”](#) and directs a project on [mitigating unequal aging](#) through community planning and design decisions. She co-edited the 2018 Hastings Center special reports [What Makes a Good Life in Late Life?](#) and [Defining Death](#) and served on the Planning Committee for the 2018 National Academy of Medicine Workshop on Physician-Assisted Death. She directed the revision of The Hastings Center’s landmark [Guidelines](#) on treatment decision-making and end-of-life care and collaborated with the Society of Hospital Medicine on a [pathway](#) for serious illness communication. With colleagues at the National University of Singapore and the University of Oxford, she co-developed the open-access [Singapore Bioethics Casebook](#). Her books include *After Harm: Medical Error and the Ethics of Forgiveness* (Johns Hopkins, 2005); *The Hastings Center Guidelines*, second edition (with Bruce Jennings and Susan M. Wolf, Oxford, 2013); and *Are Workarounds Ethical? Managing Moral Problems in Health Care Systems* (Oxford, 2016). She was a 2018 resident at the Bellagio Center of the Rockefeller Foundation for a book project on migration. She serves on the Bioethics Committee of Montefiore Medical Center (Bronx, NY) and on Montefiore’s Ethics Review Committees on hospice access for patients alone, and teaches at Lehman College, City University of New York.

## Commentary

### **Gender, Money, Systems, Stairs: How Care Works in Aging Societies**

The analysis of normative questions arising in the care of older adults in aging societies – how *should* care needs be anticipated, provided, financed, and assessed? – is strengthened when ethicists take the gerontological view. We can learn to see aging as a social process embedded in time and place (a suburb of Greater London, a city in southeastern China) and to consider the aging of a person in a time, place, and society in the context of what it has been like, over time, to be a person in that place and society. For example, adults born in the UK in the 1940s who continued to live there grew up in the context of postwar economic austerity and within the history of the National Health Service (NHS). The lives of adults born in China in the 1920s and 1930s who continued to live there were shaped by World War II, civil war, and the Cultural Revolution, all taking place before these adults entered midlife. Social gerontologist Kate de Medeiros’s 2018 essay “What Can Thinking Like a Gerontologist Bring to Bioethics?” describes how this life course perspective, familiar to her field, can support normative analysis and policy recommendations concerning the present-day and future needs of people as they move through late life at the same time. Critical analysis of contemporary social policy by gerontologists such as Christopher Phillipson and philosophers such as Alan Cribb can also support normative work by showing how policy priorities and choices – such as “austerity” aimed at health and social systems – in societies wealthy enough to have different priorities and choices can make the already precarious situations of older adults and family caregivers even more difficult. Brief comments on four themes present within and across these cases follow.

#### *Gender*

We are not surprised to see women doing the bulk of care work and care management in these cases. Alice Jones is her husband Harry’s caregiver. Their neighbor Joan shares her knowledge of local supports available to family caregivers; perhaps Joan was once in Alice’s position and had to learn this, fast. The care assistant is “she.” Alice and Harry’s daughter, Hannah, lives nearby and chides her brother, James, for “throwing money at the problem” rather than showing up as she does. While the Wu siblings expect to share in their parents’ care, Wu Qian is expected to be the one who shows up for her parents while continuing to care for her own toddler grandchildren. The family’s unnamed domestic worker is presumed to be female (worldwide nearly all domestic workers are), though the care worker they employ is male. This unnamed domestic worker is likely to be a migrant, like Beata, the Polish care worker in the home where Greta Smith lives. Greta’s daughter, Maria, like Hannah Jones and Wu Qian, lives near her parents, has family responsibilities of her own, and is expected by all to serve as the linchpin of family caregiving while a brother contributes financially. Wang Yuying was caregiver to her grandchildren, then cared for by her youngest daughter, Chen Ning, who has a physically demanding job as a waitress and does her mother’s housework. The head nurse at Wang Yuying’s care home is a woman.

Most older adults worldwide are women. Most care work, paid and unpaid, is performed by women and perceived as “women’s work.” The typical resident of a care home in the United States is a woman, because of greater longevity, therefore higher risk of dementia, and because this woman may have outlived her partner. (de Medeiros, 2018). In analyzing and comparing these cases, there is no “Western” vs. “Asian” distinction concerning who is expected to provide care: across societies, everyone looks at the woman.

### *Money*

It is both true and untrue that women do care work and men pay for it. James Jones is “happy to help [his parents] financially.” Wu Xin has supplemented his mother’s household income and paid for his parents’ house; he now pays for “the main cost of nursing care for his father.” David Smith is in and out of the picture, financially and otherwise; he initially relied on his sister, Maria, to find a care home for their mother, Greta, then asserts that he plans to find a less expensive care home closer to where he lives. (The third Smith sibling, Daniel, is content to go along with whatever makes their mother happy, keeping his distance from care work and financial support. It is unclear what Maria hopes he will “help out” with; her phone call may reflect her frustration with his avoidance of engagement.) Wang Yuying’s three sons all invite her to live with them. She rejects these offers (“I didn’t want to be a burden”) and moves to a care home; her son who lives abroad contributes more toward the cost her care to compensate for visiting less frequently.

Yet James Jones is a caregiver himself; he’s not just paying his parent’s bills as the stereotypical “distant caregiver.” He and his wife recently relocated to Edinburgh “to be closer to his wife’s family” – maybe his in-laws need care? – and “because of the time he needs to spend looking after his son’s mental health needs.” Hannah Jones appears unable or unwilling to recognize that her brother is showing up as a caregiver for his son, and indeed, must do so. Even as she dismisses his contributions as “throwing money at the problem,” she also foresees the day when “James’s money will run out.” David Smith lives 250 miles from his mother, and his involvement in his mother’s care is sporadic. The care home staff perceive him as a familiar “micro-managing” type, yet they had also expressed concerns about Greta Smith’s relationship with another resident. (The care worker’s observation that family members may become overly focused on a parent’s tea vs. coffee preferences is perplexing, given that family members are asked about such preferences at admission. As de Medeiros has pointed out, “[a] person’s current self-image may be more relevant to their care than is an impression of them from family or residential care staff.” [de Medeiros and Doyle, 2013]) David Smith’s concern about the cost of his mother’s care seems valid; what happens when those savings run out? The adult children of Wang Yuying and of Wu Haichuan and Huang Ning are presented as better able to collaborate with one another about doing and paying for care work, compared to their English counterparts. Although the hands-on work is gendered, paying one’s fair share, including paying more to compensate for less day to day involvement, is presented as a necessary and important care responsibility within the Chinese families.

### *Systems*

Each of the cases provides some details concerning local systems for supporting care in the home or a care facility. The Jones family case offers significant detail on how social policy shapes the experiences of aging and caregiving. Harry and Alice Jones live on their state pensions; they have little savings and they rent their house, therefore they have no accrued wealth in the form of equity. A knowledgeable and helpful neighbor advises them to contact the local council for publicly funded care assistance for Harry plus a Carer's Allowance for Alice. The Jones's household life is reorganized around the demands of the system, as the care assistant arrives twice daily at fixed times. While this schedule is justifiable from the system's perspective – the care assistant must provide similar services to other clients – it disrupts Harry's routine in ways he cannot understand given his cognitive condition. The presence of different care assistants adds to Harry's confusion and distress and Alice's sense of "shame" at having to rely on rotating "strangers." And yet what choice do they have? Then comes the bureaucratic cruelty of the reassessment. A funding cut to care services means Harry no longer has a care assistant for the morning. This is laughably justified by a needs assessment finding that a man in progressive cognitive decline no longer needs help going "downstairs" – as if this was the only help he needed, as if his wife's back has miraculously healed. The funding cut is bad enough; the lie that blames it on the person in need of care is morally bankrupt. Ethical analysis of care roles and responsibilities in aging societies is remiss if it fails to account for the policy choices of wealthy and unequal societies. Recent work on how austerity warps professionalism (Owens, Singh, Cribb 2019) provides crucial background for understanding, if not being able to resolve, cases like this.

### *Stairs*

Stairs loom large in aging societies. So many of Harry and Alice's current problems arise because they live in a typical terraced house with stairs. An environmental gerontologist or a housing policy expert reading the Jones family case would ask, is there any way Harry and Alice can move to a house or flat without stairs, and ideally with other design features – walk-in showers with grab bars, kitchen cupboards that are reachable without bending or stepstools? Can Harry's bedroom be moved downstairs? (If the bath is upstairs, that solution will not work.)

The "future care" of older adults involves thinking about a community's housing stock – is it being designed and built for an aging society, mindful that the home is the primary site of care – and living – for older adults? These issues of "spatial justice" also touch on decisions about financing for public libraries, transportation, and other community services that are not formal care services but whose presence or absence shapes the lives of older adults and family caregivers.

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### **Jean Woo**

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### **Commentary**

The four case studies cover home care and residential care in the UK compared with China. All four cases have common themes, which will be explored in the following sections.

#### ***Looking after older people who are dependent on others: is there really a cultural difference***

Comparative literature examining societal response to care of older adults in aging populations frequently emphasize the key role of families in Eastern cultures, and ageist attitudes in Western cultures. Filial piety as a characteristic of Chinese culture is actually historical, and actually more like a myth perpetuated by societies who avoid the long term care burden. The traditional culture of filial piety stems from Confucianism, and has been frequently promoted as key to long term care for older people among Chinese cultures. However looking after ones parents is not unique to the Chinese culture. Advocacy of filial piety has adverse consequences in stifling real challenges of aging populations and development of newer models of long term care, in creating problems in end of life care scenarios, and accentuates carer stress and older person's perception of burden to family and society. In fact negative attitudes toward older people may be more prominent among Chinese societies compared to some Western societies, as documented by recent data from Hong Kong [Mak et al 2011]. Attitude of filial piety is not supported by behavior. A cross cultural analysis of 21,093 participants from 23 countries, show that Eastern cultures do not hold older adults in higher esteem (even when they supposedly have stronger collectivist traditions of filial piety); in fact attitudes were more negative in the East

[North & fiske 2015; Löckenhoff et al 2009, 2015]. A recent rise in population aging appears to predict negative attitudes, while cultural individualism predicts positive attitudes. There may be a U shape relationship between positive attitude and economic development. All four cases illustrate the commitment of family members to caring for their parent, whether in time or monetary terms, in both the UK and China, to accommodate this role as much as possible within their daily lives and responsibilities.

### ***Home care is better than residential care***

A common perception is that ageing in place is a desirable feature of successful aging. The term refers to the ability to remain living in the same environment without the need to re-locate as a consequence of ageing and accompanying physical or cognitive functional changes, if any. In practice this often interpreted as staying in one's home for as long as possible with support. A prerequisite for aging in place is a mechanism to detect unmet needs. Many healthcare systems do not include systematic screening for such needs, in particular early identification of common geriatric syndromes such as frailty, sarcopenia, anorexia, mild cognitive impairment, and depression. These conditions may predispose to functional decline, hence the call for rapid geriatric assessments in the community [Morley 2015]. A recent survey among 2400 older persons aged 60 years and over attending community centres in Hong Kong showed high prevalence of unmet needs, with memory problems, chewing difficulties and pre-frailty and frailty being the most common problems (74%,63%, and 38% respectively), while approximately 20% reported low subjective well-being, had problems with instrumental activities of daily living as well as insufficient income [Cheung et al 2018].

It follows that ageing in place is only desirable if conditions are met to optimize function to enable coping with common chronic disabling diseases such as arthritis, stroke, as well as age-related syndromes such as sensory impairment, chewing difficulties, cognitive impairments (such as deficits in the domains of memory; processing speed; executive function), impairments in instrumental activities of daily living, physical function, and psychosocial needs. Desirable goals with respect to aging in place include optimizing function by manipulating home design, furniture and aids, and reduction in isolation with the help of social network/support as well as technology. For the majority of people, ageing in place will be synonymous with home-living; however this may not be possible and moving to a more enabling environment purpose built care facility may be indicated to optimize care in the face of physical and cognitive dependency. Whether home care or residential care is the best option depends on the health and social care systems of the country, and whether adequate assessment had been carried out to identify care needs.

The two case studies on home care illustrate show that there are deficiencies in the home care systems in both UK and China. The case in the UK illustrates the failure to identify needs properly: installation of a chair lift for the stairs would go a long way towards relieving carer burden, as well as regular attendance at dementia day care centres with provided transport. In China there is rapid development of private organizations providing various types of home and day centre care.

Long term care in residential care settings are of varying standards. The case study in China highlights an important positive feature of the power of social engagement in the institutional community: older people may prefer such settings rather than be a burden on their children, as they also 'have a hard life'.

### ***Person-centred rather than one model fits all***

These cases illustrate that long term care decisions is a team process involving the older person, the family, and health and social care systems. What is important is the need to continue to highlight what the unmet needs are and work out flexible solutions rather than put people in need into rigid systems to be processed.

### ***Funding source and concept of collective societal responsibility***

Other than designing models of home and residential care systems that are person centred, financing is a major hurdle to overcome. No government will be able to provide for needs from taxation. The insurance industry needs to be engaged to develop various products analogous to expenses for medication, investigations, hospital stay, towards products as personal care, day care, institutional care, end of life care, possibly linked to reduced premiums based on a person's participation in mid life health promoting activities. Private companies will also have an important role. Public health promotion about maintaining functional independence and source of care and training for long term care are also relevant for those in mid life and early post retirement, as they are likely to become carers before they become dependent on others.

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### **Tom Walker**

Dr Tom Walker is a senior lecturer in ethics at Queen's University Belfast. His recent work has focused primarily on ethical issues raised when supporting people with chronic conditions. This has resulted in a book *Ethics and Chronic Illness* recently published by Routledge.

### **Commentary**

In this commentary I want to focus on two issues: the use of technology (specifically the use of cameras in case studies 3 and 4); and the topic of who has responsibility for providing assistance to older adults (a topic that came up in all four cases).

#### *Cameras in care homes*

Both residential care cases (cases 3 and 4) briefly mention discussions about installing cameras. In practice this issue is not restricted to residential settings. With the development of new technologies (and a move towards digital care) incorporating sensing technologies in home care is becoming a real possibility. The ethical issues raised here are typically framed, at least in the UK, as a conflict between safety and privacy. On the one hand, there is a concern to protect the safety and wellbeing of older people and new technologies can help with that. On the other, cameras (and other sensors) pose a potential threat to the privacy of residents (and staff). Decisions about whether or not to instal these kinds of technology thus require balancing competing values. The outcome will largely rest on details of the specific case.

However, it was noticeable that in both cases (3 and 4) the only people mentioned as being involved in the decision were members of the resident's family and/ or staff in the residential home. Neither mentioned the residents themselves. That is ethically problematic for two reasons. First, even when people who are differently situated agree on what values are significant, they can disagree about the weights to be put on those values. For example, when thinking about their parents people may place more emphasis on safety and wellbeing, and on the benefits that new technology can produce (this seems to be the case with Maria in case 3). In contrast, the older people themselves may have other concerns and other priorities. As such, there is a risk that decisions made ostensibly for the wellbeing of older people fail to take account of what matters most to them. The second, and potentially more significant, problem is that excluding residents from an active role in decision making constitutes a failure to acknowledge them as equal moral agents. The decision makers are effectively signalling that they think it appropriate to make decisions on behalf of older people, rather than with them. The risk of these sorts of messages being sent is particularly acute in ageist societies (like the UK) where a set of stereotypes exist characterising older people as cognitively impaired, something that is perhaps even more the case for those living in residential homes. But the residents in cases 3 and 4 are not cognitively impaired. It is thus inappropriate to exclude them from decisions that primarily concern them.

### *Responsibilities and families*

All four cases involve older people who have children. Some of the tensions outlined appear to arise from unstated differences in each person's conception of what responsibilities children have when it comes to supporting their parents. In philosophy in the UK (and similar countries) whether children have such responsibilities is sometimes contested. Even where it is not, there remain disagreements about the source of such responsibilities. These can be split into three main categories (all of which are reflected in different case studies). First, there are accounts that say children have this responsibility because their parents provided significant benefits to them in the past, sometimes at great cost (an idea expressed by Chen Ning in case 4). The underlying thought here is either that there is a debt that children should repay, or that helping is an appropriate way to show gratitude for past benefits. Second, there are accounts that say children have this responsibility due to an ongoing relationship with their parents. While often characterised as 'friendship' accounts, the relationship is not best thought of as a form of friendship. The basic idea is that being in a relationship of a certain type brings with it responsibilities and obligations — ones that arise from that relationship. Finally, there are broadly consequentialist accounts that place the responsibility on children because they are best placed to know what will most benefit their parents, in part because they know their parents well (a view expressed in case 3).

However, focusing on the responsibilities of children can blind us to the responsibilities of the wider community. That there are such wider responsibilities becomes more apparent when we consider the increasing proportion of older people (at least in countries like the UK) who are childless. Arguably the key value here, at least in a European context, is solidarity — the idea that all those within a community have a responsibility to support and help those who require that support. That is, while family members may have some responsibility to support their older relatives, that responsibility should not fall on them alone. Even those who challenge the idea that solidarity is a value that should be promoted (which they may do on the basis of the sometimes divisive effects of appeals to solidarity), will have good reason to support such collective responsibility in practice. Each of those who are still young will likely become older and, if they do, will have a fairly high chance of needing support. Self-interest alone should thus lead them to support community level provision. An alternative to relying on the value of solidarity is to argue that this kind of community level provision is a requirement of justice. That could be done using a capabilities approach of the kind developed by Amartya Sen and Martha Nussbaum. According to such an approach justice requires ensuring that everyone has a specified set of capabilities — which we can think of as the effective freedom to do or be certain things. On this account there is nothing special about being older. Rather it is that justice requires certain types of support for older people, support they may not receive because their reduced capabilities are treated as in some sense 'natural' or 'normal'.

## Rueben Warren

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### Commentary

#### Care Ethics and Older Adults

Care ethics, grounded in feminist and moral theory, focuses largely on caring for the *other*. It challenges masculine thinking and argues that interdependence, rather independence is the greater value. Care ethics is sometimes viewed as a form of virtue ethics. Care is value and practice. The four cases studies may differ in geographic locale, culture, any/or situational specifics. However, there are common themes from which to highlight **practice, policy and philosophy** associated with the care of older adults as individuals, and as a demographic group. Some of the themes are: health and quality of life challenges of older adults, highlighting sex differences; siblings caring for elderly parents and for their primary families; policies on public/private infrastructure support for the elderly; and public health ethics and aging research for population health. Public health ethics interrogates the common themes highlighted in the case studies for elders, as a global demographic group.

Bayer et al write, *“public health ethics, emphasizes the ethical problematic related to interests and health of groups, the social justice of the distribution of social resources, and the positive or social rights of individual. The study of public health ethics requires the practitioner to effectively conceptualize and operate between the tension of individual rights and collective interest.”* These case studies highlight several generalizable challenges confronting elders, the fair distribution of social resources, and the lessons learned from each. The health challenges, while individualized, are plausibly generalizable to the larger elderly population. Health described in this commentary is, *“the physical, social, psychological and spiritual well-being of the individual and group in their social and physical environment.”* In each case study the elderly husband’s failing health has the spouse, adult children and their families challenged to determine fair and right actions for their parents. As the husband’s health deteriorates, the adverse physical and mental health of his spouse, the varying and tense interpersonal relationships between the adult siblings, and the socio-economic impact on elderly/sibling families require compromise. There are shortcomings in public policy related to elder healthcare and social support. Globally, public policy is inadequate to respond to an aging global society.

#### *Health and Quality of Life Challenges of Older Adults.*

Globally, life expectancy is increasing. Older adults however, are at greater risk compared to their younger counterparts because of the usual physical and mental changes that accompany aging. Public policy for older adults has not adjusted to more people living longer. Consequently, public and private practice to care for this group also is inadequate. A paradigm shift to synergize public health ethics and care ethics is needed for the elderly. Public health ethics demands redistributing social

resources, honouring the social rights of individuals and assuring social justice. Women live longer than men do, they access health care more, and their quality of life is usually better. While marriage enhances the well-being of both sexes, due to excess adult male morbidity and mortality, the case studies highlight the adverse consequences that female spouses experience, as caregivers. Care ethics encompasses a moral theory that is grounded in relationships and virtue.

#### *Sibling Roles and Responsibilities for the Care of Elderly Parents and Their Primary Families.*

The case studies describe possible sibling differences, plausibly developed during their youth, different perspectives on siblings' care roles, and varying ideas about parents' autonomy on deciding what is best. They also differ on the shortcoming of the social support systems for elders. Private versus public support systems, including healthcare differ and the siblings have little confidence in either. Synergizing siblings' contributions for the best interest of their parents is a problem. There is tension between the siblings in each case study on the value, relevance and importance of the different siblings' contributions for the best interest of their parents. The sibling rivalry inhibits reaching consensus, particularly after the death of the husband/father. The problems seem unresolvable because of different views of the siblings that block comprise. The female siblings rely on personally caring for and interpersonal relationships with their parents, which are consistent with care ethics. The male siblings prefer arranging or paying for care which is consistent with other dominant moral theories that care ethics challenges.

#### *Public/Private Policy Related to Infrastructure Support for the Elderly.*

Infrastructure support for an aging population is a global challenge. The United States spends more money on medical care than any other industrialized country. Yet, the U.S. ranks poorly in population health outcomes, compared to other industrialized countries. U.S. health care purports to be among the best in the world, yet only 15% of health care is attributed to health. As one ages, so does curative health care expenditures become disproportionately higher for the elderly. More health-related research on aging, including disease prevention and health promotion is likely to reduce curative care costs while improving health and well-being of the aging population.

#### *Public Health Ethics Implications for Aging Research*

Health improvements for elders begin by identifying the populations at greatest risk and discerning the conditions that place them at risk. After the science, a paradigm shift to an ethical analysis, including a care ethics assessment of philosophy, policy, and practice related to caring for the elderly, in that order, is needed. For example, among older adults, Alzheimer's disease (AD) is a growing global mental health problem. Older African Americans (50 and older) are twice as likely to have AD compared to older non-Hispanic white Americans (NHW), but the reason for this is not clear. More aging research is needed on African American and AD. Yet, African Americans only represent 8% of participants in AD clinical trials and observational studies, despite accounting for more than 20% of AD cases. Furthermore, African

Americans who participate in major AD studies are on average healthier than their NHW counterparts, and are 60% more likely to drop out. Ethics research can assist in understanding this issue. Philosophically, valuing human life is the intrinsic claim for justice of everything that has being. Policies that honor justice will more likely result in ethical practice.

### **Jing-Bao Nie**

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### **Commentary**

#### **A Confucian Vision of Social Eldercare: *Xiao* (Filial Piety) as a Duty of the State**

Jing-Bao Nie and Xiang Zou

The proverb “it takes a village to raise a child” has become very well-known. Feminist, former State Secretary and first lady Hillary Clinton has help popularize the saying from several indigenous African culture in the West through her 1996 book thus titled on the shared social responsibility of looking after children in the United States. This communitarian spirit is common in other indigenous cultures such as Maoris in New Zealand. The ideal does not limit to child raising, is and should be employed to many other areas of human life. It is high time to expand the vision and wisdom of this old maxim in the area of the elderly care, from the beginning of life to the other end of life. All four all-too-real and poignant cases studies demonstrate such an urgent need.

Partly due to its prominence in Confucianism, the norm of *xiao* (commonly translated as “filial piety”) has been widely characterised to be a salient feature of East-Asian cultures. It has been frequently invoked in discussing ethical, legal and public policy issues of health care, especially those arising from aging population and eldercare. The head nurse as caregiver in Case Study 4 indeed directly invoked this norm when she communicated with the children of care-receiver Mrs. Wang. This is an important ethical norm underlying the two cases from China.

The standard definition and interpretation of *xiao* focuses primarily upon a younger member’s duties to the elderly within the family, and the word “filial” in the English translation of the term has plainly captured this focus.

However, based on the primary work by Mengzi (Mencius) in the 4<sup>th</sup> century BCE, the co-founder of Confucianism, one can argue that the age-old Confucian or East-Asian value “*xiao*” offers a vision of social eldercare. A broader and social understanding of *xiao* defines it as an essential duty of the state to each and every senior citizen in the society. *Xiao* thus means duty of care to the elder in one’s family as well as other elders in one’s community and society.

To re-conceptualize *xiao* in such a manner would appear to be very strange or at least unauthentic to Confucianism and East-Asian cultural traditions. Yet, for Mengzi, this is one essential dimension of *xiao*, though as yet to be appreciated. A house-hold Chinese proverb put forward originally by Mengzi states: “Treat with the care due to age the elders in your own family, so that the elders in the families of others should be similarly treated; treat with the care due to children the young in your own family, so that the young in the families of others should be similarly treated (老吾老以及人之老，幼吾幼以及人之幼)”. This statement points out not only the parallels between childcare and eldercare but the necessity of extending the virtue of filial piety to the wider community and society. Mengzi made the statement in the context of advising a *king* on how to realise good governance and benevolent in everyday practice.

For both Kongzi (Confucius) and Mengzi, King Shun and King Wen were two exemplary leaders whose leadership embodies the key political and moral ideals of Confucianism. King Shun, one of five legendary kings who lived more than four thousand years ago, is praised for respecting and caring for his father and brother despite their abusive behaviour. More importantly, King Shun extended his practice of filial piety to the people of his kingdom, particularly the elders and those in need. King Wen lived more than three thousand years ago. For Mengzi, a defining attribute of King Wen’s reign was *shan yanglao* (善養老, excellence in taking good care of old people or knowing how to care for the elderly). While Mengzi did not give us any detail, one can discern that the eldercare programmes of King Shun and King Wen are community-based and social eldercare.

One may think that Mengzi’s outlook will inevitably endorse the contemporary polity of the welfare state, or even socialism and statism. This can be the case but is not necessarily so. The key point here is that, at least for Mencius, it is not the state itself that should be empowered. Rather, the moral and political obligation of the state is to empower the people so that the elderly are looked after, through their active individual and communal participation in giving and receiving care. In other words, the state has a duty to develop the favourable social, institutional, economic and cultural environments in which people are able to care for the elderly and practice the cardinal virtue of filial piety, to not only their own parents and grandparents but other older people in one’s community and society.

The Confucian vision of social eldercare founded upon the old norm *xiao* has a number of implications for developing better elderly care in today’s world. As the four cases occurred in China and the UK indicate, more adequate social support for care receivers and especially family care givers is much needed. In the context of China,

the Confucian understanding of xiao as a basic duty of the state highlights some serious failings of the state in the area of the elderly care. They include the extremely high suicides rates among the older people, especially in rural areas.

Great challenges of eldercare in rural China ....

### **Emiko Konishi**

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### **Commentary**

★Overall comments re major themes in the four cases:

-Levels for elder care: could be divided into 3 broad levels: A) national support, B) mutual help in community, and C) self help within family. All the 4 cases depict children's struggle in the C level with some neighbor's help like in case 1. With limited access to information about care system and A-B level supports, the families, towards the end of the stories, might come to a deadlock. What happens next to the entire families is very worrisome. Need for more A-B level support is apparent.  
-Japan example in this regard, although far from ok.

A) National support: Long Term Care Insurance system enforced in 2000, see attached.

\* This system has changed the Japanese culture to some extent: People used to be unwilling to have outsiders into their private territory, but now they see this as their entitlement

\*\* Increasing budget pressure: According to a small survey about young people's opinion, 75% of those surveyed supported budget increase for LTC because they see the problem as their own in future.

B) Mutual help in community: With a traditional communitarian culture, community network for mutual help is still functioning particularly in rural areas. Each block of a municipality has a Local Elderly Care Management Center where professionals including public health nurses (PHN) and PT/OT work. PHNs regularly hold health classes for elderly, young mothers, and/or the mentally vulnerable people: health checkup, teaching, medical-welfare system information giving, referrals to local professionals. Also appointed in each block are non-professional District Welfare Officers (DWOs) who work part-time with small public money by the Commissioned Welfare Volunteers Act. Problem cases found by the DWOs through their regular rounds and everyday talks with people in the community are connected to PHNs.

\* Two Major barriers for community network: 1) Information Privacy Protection Act 2003, and 2) more people live in apartment buildings even in rural areas.

★ Case 1 - Japan has the same problem. The real problem resides in the last paragraph. Two options for the problem may be:

- a) Parents move to London to live with their daughter Hannah—Without a well developed home care system like in Sweden, this idea seems to be very difficult: Parent not wanting to burden her daughter, Hannah's house not spacious enough, parents not wanting to leave their hometown.
- b) Parent alone or with the spouse move to residential care in their home town –This seems to be only the option. System like LTC Japan might help to some degree.

★Case 2 - Painstaking effort by children will soon collapse. What happens next? Japan has a word 'care leave' ('Kaigo rishoku', meaning to give up my job to take care of my parents).

★Case 3 - is similar to Japanese situation: old mother, while not expressing her feeling much, develops dementia, and some particular child like Maria takes 'care leave' for her Mom out of her moral commitment. A distant family member like David abruptly intervenes in the situation. Also, residents' intimate relationships are not rare in residential care in Japan. If case 3 was brought to a PHN in a Japanese community, she would approach the case by a 'do good' (paternalistic) rather than an autonomy model, so that as Daniel says, Mom can stay where she is, because Mom seems to be happy there, and to change the care environment at this time would be a huge stress to the frail Mom. The PHN also gives information about LTC system to the children so that their ADL impaired parents can be covered by this system. Maria's two brothers who keep distance from the care responsibility should pay for the rest. During the coordination process, disagreements among the family members might occur, and I hope that this PHN could harmonize them by borrowing Beata's warm remark about family involvement.

★Case 4 - Japan shares the following similar traditional values but those values are getting weaker in the complexity of present society.

- Filial piety: Wang's children seem to be more committed to their parents than some Japanese counterparts who visit their parent(s) at first, but later, gradually less frequently. As parent(s) live longer, filial piety is getting more and more an ideal among most of the younger generation, excepting well-off families. Some Japanese children even rely on their parent's pension for their living.

- Old parents' wish not to burden their children—This value is still very strong among Japanese old people. Indeed, it is for this very reason that most of the residents here have decided to move to our present senior living to spend the remainder of life.

- Family first pattern of healthcare information giving---The term Informed Consent is known among Japanese professionals. But the knowledge is superficial particularly among elder care staff, and common disclosure pattern among them is to family first and old parent later or never.

- Monitoring elders' behaviours by some electronic sensor is quite common practice in a Japanese dementia institution: safety first over the residents' freedom and

dignity. Much discussion and research against this practice is going on but constraints such as limited human/financial resources make it difficult to solve the problem.

### **Hsiung Ping-Chen**

Professor Hsiung Ping-chen is Professor of History and Director of the Taiwan Research Centre at the Chinese University of Hong Kong. Her main research interest lies in the area of women's and children's health. Her works included *Paediatrics and Early Education: A History of Reproductive Strategies of Chinese Society*, *A Tender Voyage: Children and Childhood in Late Imperial China* and *Childhood in the Past: A History of Chinese Children*. Hsiung Ping-chen is CIPSH Chair in New Humanities, University of California, Irvine and President, Asian New Humanities Net (ANHN)

### **Commentary**

How people had been aging and handling aging differently in time, and how innovative research methods need to be employed to investigate this?

The specific case of early modern China was chosen because of the juxtaposition of two factors: One, Chinese society, following Confucian family ethics and ancestral worship has been referred to as one most reverent to its seniors members, a fact as myth to be verified. Two, since its late imperial period (16-18<sup>th</sup> century), it is also known to have experienced an outstanding population explosion (with a phenomenal triple growth from roughly 1.8 billion to 4.5 billion).

These two elements, examined together not only the old Chinese legend of respecting the seniors, both the old and the young of the contemporary population would be compelled to consider in practical terms of the "how to" in the daily life in managing the increasingly prominent phenomenon of more and more people growing older and older, in an ever greater number. Methodologically I choose to begin this in a textual study on contemporary wisdom or "advice literature" from the 18<sup>th</sup> century (the Ch'ien-lung era of the Ching Dynasty, 1644-1911), as a best textual evidence. In so doing, it hopes to demonstrate how such investigation needs to be informed by social sciences and natural sciences in its approach as socio-cultural history interacts with historical, behavioral science, and life course studies.

#### *Aging and Advice literature from 18<sup>th</sup> century China.*

It examines the instructive and experiential aspects of what it meant to be growing old and caring for the growing aging population during Late Imperial China, to establish the factors of both "age" and "phases of life" in Chinese history. That is, even though modern social sciences and humanities affirm the importance of (1) "age" in the lives of individuals and societies; and of (2) how life course in stages as critical organizing elements of society, historians need to develop the interest and methodology to approach these questions productively. The 17<sup>th</sup>–19<sup>th</sup> centuries appear a useful period for such an investigation, since the decline of infant and adult mortality and the increase of average life expectancy had created a rapidly growing population, with an expanding aging group. The advice literature together with

chronological biography data during this period, presented the textual bases to explaining how “aging” and “seniority” emerged as changing historical forces for the late imperial Chinese society.

I like to demonstrate that the demographic breakthrough in aging in this period prompted a culture of self-care and mutual aid, as succinctly suggested in the work of Ts’ao T’ing-tung’s (曹庭棟, 1700–1785) *Advice for Aging* (*lao-lao-heng-yen*, hereto LLHY). Categorically, this pragmatic daily homily on aging indicated a separation from the old Taoist pursuit of longevity and immortality. It marked also a departure from the Sung-Yüan-Ming Confucian instruction for the juniors to bear to main burden to care for the needs of their parents and family elders. This study will show that by the 18th century, a new wave of “self-care” emerged in the advice literature in place of or in addition to the earlier expectations of “old age care” by the juniors. On the practice side, systematic examination of experiences in aging and the practice of old-age care as evidenced in hundreds of chronological biographies (*nien-p’u*), will empirically yield a micro-level picture on for this personal and familial practices of aging and old age care to be re-considered as a pre-modern testimony to a mostly-believed-to-be modern or post-modern phenomenon. Comparative observations between these findings on aging and old age care and those from other societies (such as colonial America and early modern England) can be made to elucidate its cross-cultural implications.

The 17th –19th centuries appear a productive period for such an investigation, since the decline of infant and adult mortality rates and the increase of average life expectancy had created a rapidly growing population, also with an expanding aging group. Thus just like pediatric manuals, personal biographical chronologies, and family records produced a documented history for infancy and childhood after the Sung (960–1279) that it had studied, advice literature and chronological biography data since the Ming (1368–1644) presented the textual bases to establish how “aging” and “seniority” emerged as changing historical forces for the late imperial Chinese society

Philological work and textual studies show that handbooks of “self-care” and “self-aid” presented, first of all, a clear break from earlier Taoist traditions of “manuals for longevity” in pursuit of immortality. Religiosity aside, on the social life and domestic scene, such self-help books in old age care also marked an important departure from the older Confucian advocacy from the Sung-Yüan-Ming period asking the filial juniors to provide for their aging parents and elders. Even though both these Taoist texts and the Confucian manuals continued to be reproduced, from which the 18th century texts such as LLHY drew part of its references and inspiration, initial study demonstrates that the quantitative breakthrough demographically in aging, along with the socio-cultural momentum demanded new responses which prompted a culture of self-care and mutual aid among some seniors themselves, as succinctly suggested in the title of LLHY (i.e., the novel idea of “lao-lao,” to help with one’s own old age, and to help that of each other’s as people get on with “aging.”). For which a different literature emerges “on the cultural

market” just as the chronological biography (*nien-p'u*) data and family genealogies serve as its qualitative testimony.

That is, even though aging as an outstanding phenomenon is mostly derivative of modernity, and that historical China being no exception, that is not to say that demographically, there had not been senior populations or that there lacks a history of caring for them. Culturally and philosophically speaking, Chinese society has been referred to as one that reveres its elderly as it worships its ancestors and yields to the seniors. As to whether or how historical records may be made to bear out this myth or conviction, systematic examination is needed. This essay intends to examine the advice literature (as well as the practice of aging) during the early modern era, i.e. late imperial period (17th–19<sup>th</sup> centuries), when demographic explosion and a refashioning of old age care became evident.

My past thirty years of research on the history of childhood and the knowledge and experience thus gained. Structurally, in terms of human life course, childhood and seniority represent two opposite ends of the life span. In my study of children and childhood in late imperial China, which resulted in three monographs in Chinese and one in English, I had relied on medical, social, and philosophical texts as well as art history and other materials. Conceptually speaking, this study aims also at opening our understanding of aging during a similar period of Chinese history, with an evolving cultural construct beyond the stereotypical impression.

My familiarity with the source materials in medical history, health records, historical demography, and disease history will save much time in data collecting. The auto-biographical and bio-graphical records as well as family and clan instructions and genealogies such as chronological biography, the *nien-p'u* (年譜), *chia-p'u* (家譜) and *tsu-p'u* (族譜), like patterns of regional, class, and gender differences in childhood history uncovered earlier, even though with build-in constraints, are critical in providing a baseline for this research.

This attempt begins with a study on the Advice for Aging (*Lao-lao-heng-yen* 老老恆言 LLHY) by Ts'ao T'ing-tung as a key text. The preface of its 1870 edition introduced its author Ts'ao as coming from a comfortably landed family of the Chia-shan County of Che-chiang Province. Though without much success in the civil service examination, or officialdom, Ts'ao belonged to the rank of China's sizable educated gentry-scholars with a knowledge in Confucian classics and a grasp of traditional Chinese medicine and pharmacopeia (*pen-tsao* 本草), also a familiarity both in the Taoist literature on cultivation of longevity and the Confucian demand on caring for one's aging parents.

Other traits of Ts'ao's life suggested one growing up immersed in Confucian ethics, known as a filial son. In his late forties (9th year of Ch'ien-lung, i.e. 1744), out of boredom, he had laborers dragging out mud from the riverbed to create a mount in his garden. What had started as simple pleasure later appeared in his *nien-p'u* as an

act of filial piety. “Since this happened to take place on my mother’s birthday,” Ts’ao noted, “I decided to name this the “Mount of Motherly Compassion (慈山*t’zu-shang*),” to make his remembrance of her. Shortly thereafter, Ts’ao started calling himself the “Humble man from the Mount of Motherly Compassion (慈山居士*t’zu-shang chü-shih*)”, a name he wore ever since as a tribute from a filial son. As Ts’ao continued to write profusely about the creation of this mount, in 1744, the significance of this title looms large, with strings of celebrative poems trailing.

Another element related to his writing on aging and life in general is that Ts’ao was known to have had an ailing childhood. Both his autobiographical account and that of acquaintance prefacing his works mentioned his suffering from chronic lung disease and a weak physique while young, which helped to bring to relief his later interest in the question of physical well-being, regarding which his high seniority later came as no small significance.

In his pursuit of aging, even though there remains some dispute in exactly how old Ts’ao had lived to (some said well into his nineties), there appears little doubt to the personal interest he had taken on the subject, since he was known to be publishing well into his eighties on this issue. The virtue of a filial son, the memory of a frail youth, could all be made to add to the claim on the “secret” that an old man gained on aging, which surfaced at a time when an ever growing number of others were also emerging rapidly bearing similar interests.

In terms of its content, LLHY includes much of daily homilies in the physical care of the old, just like the over three hundred references on how best to deal with aging that Ts’ao appendices at the end. A closer reading of his own text reveals, however, important differences. Because, the first four chapters (*chüan*) of his book noted what seems the ordinary how-to in way of self-care, much more so than on the care of one’s parents or family elders. Certainly none was produced looking for longevity or immortality.

Hereby lies the critical change appeared in this 18th century text and from its medieval predecessors. For its appearance marked a particular moment in China’s demographic history when the decline in mortality helped to produce an ever growing number of the aging, both as a group in need also a new audience with focused attention, for the advocacy of old age self-care and mutual aid, not necessarily waiting for or relying on the provision of one’s offspring or juniors. Chapter one includes eight items of these recommendations, on how best to conduct one’s own eating and sleeping, getting up and taking walks. Chapter two, on how to get on with one’s exercise, making excursions, for the prevention of diseases and in the self-education for taking medication. Chapter three, on one’s own suitable furniture and clothing, as well as other ordinary equipment and set-ups. Chapter four, on one’s bed chamber, bedding, pillow, mosquito net, quilts and cover. Chapter five consists of a special instruction, on the making and consumption of congee (粥譜), that the author added to Advice for Aging the year after its first completion, which later was often printed as a separate booklet.

A contextualized reading of the table of content of this Advice for Aging helps us to better recognize this subtle but significant re-orientation and representation, as we appreciate the sociological and demographic forces behind this cultural production. For this conceptual and substantive divergence it exhibited, in contrast both to the Taoist longevity manuals it inherited, and to the Confucian or medical texts prescribing for the care of the parents, it deserves a complete listing of the 5 chapters and 42 items can be revealing:

Chapter 1 (卷一): Sleeping 安寢(*An Ch'in*); Morning Rise 晨興(*Ch'en Hsing*); Washing 盥洗(*Kuan Hsi*); Eating and Drinking 飲食(*Yin Shih*); Food 食物(*Shih Wu*); Take Walk 散步(*San Pu*); Napping during the day 晝臥(*Chou Wo*); Setting up at night 夜坐(*Yeh Tso*) (in 8 items).

Chapter 2 (卷二): Resting 燕居(*Yan Chü*); Light Hearted 省心(*Sheng Hsin*); Receiving the Guests 見客(*Chien K'o*); Visiting 出門(*Ch'u Men*); Preventing disease 防疾(*Fang Chi*); Caution for medication 慎藥(*Shen Yao*); Pastime 消遣(*Hsiao Ch'ien*); Exercises 導引(*Tao Yin*) (in 8 items).

Chapter 3 (卷三): Study 書室(*Shu Shih*); Desk 書几(*Shu Chi*); Sitting Chair 坐榻(*Tso T'a*); Crane 杖(*Chang*); Cloth 衣(*I*); Hat 帽(*Mao*); Belt 帶(*Tai*); Sock 襪(*Wa*); Shoes 鞋(*Hsieh*); Miscellaneous equipment 雜器(*Tsa Ch'i*) (in 10 items).

Chapter 4 (卷四): Bed Chamber 臥房(*Wo Fang*); Bed 床(*Ch'uang*); Net 帳(*Chang*); Pillow 枕(*Chen*); Mat 席(*Hsi*); Cover or quilt 被(*Pei*); Undersheet 褥(*Ju*); Chamber pot 便器(*Pien Ch'i*) (in 8 items).

Chapter 5 (卷五): Congee 粥譜說(*Chou P'u Shui*); Rice 擇米第一(*Tse Mi Ti I*); Water 擇水第二(*Tse Shui Ti erh*); Fire 火候第三(*Huo Hou Ti San*); Cook 食候第四(*Shih Hou Ti Ssu*); Best 上品三十六(*Shang P'in San Shih Liu*); Medium 中品二十七(*Chung P'in erh Shih Ch'i*); Lower 下品三十七(*Hsia P'in San Shih Ch'i*) (in 8 items).

Considering the time period it represented, as well as the geographic region and socio-economic standing behind this particular text, a few points worth special attention. First of all, by the 18th Century, China's population explosion established for the Ch'ien-lung period included a decrease in infant and adult mortalities and a due increase in the total population which brought along an ever growing number of post-middle age people in need of care, of which the prosperous and affluent Lower-Yangtze valley region represented a key concentration. Secondly, textual study suggests that there exhibited a clear "secular turn" in the philosophy behind this advice literature in its fashioning of a spirit of self-reliance in the caring of the old. Because even though inheriting in spirit and in content from China's century old Taoist tradition in the cultivation of longevity, the emphasis here presents a clear break away from the pursuit of immortality. Rather it focuses on the very pragmatic need of meticulous, even tedious details in the daily care of a human body that is physically getting on in age. Considerations such task as the way to help dressing an older person (mostly a male), the appropriate shoes to put on, assistance for a better sleep, how best to wash one self, the kind of cranes to walk with, the sort of hats to

bring along, the physical exercises advisable, the furniture and bedding equipment suitable to have, even the chamber pots at one's convenience at night, caution for taking medication, or the preparation of congee, what LLHY enclosed and advanced for that society's aging population was to teach them to help themselves, not waiting around to be cared for.

Which marked a critical departure from the Chinese tradition, suggesting an emerging culture of aging interested in self-care, no longer following the good old virtue dependent of filial piety of others, as the Yuan medical text *The Confucian Way of Serving One's Parents* (儒門事親) used to advocate, or *New Book on the Looking after the Old and Caring for One's Parents* (壽親養老新書) had been prepared for.

### **Alison Armstrong**

Dr Alison Armstrong is Director of Research for The Whiteley Foundation for Ageing Well, based at the Whiteley Village retirement community. Her role is to collaborate with residents, staff and external organisations to conduct research that, when operationalised, can improve the lives of older citizens and those that work with them. She also runs a well-being training company. She completed her PhD in social psychology at the University of Surrey in 2012.

### **Commentary**

I write this commentary from my professional perspective of working in the Whiteley Village Retirement Community. My role is a research one, however, I am learning daily about the challenges of care provision for older people. The views expressed here are my own, not necessarily those of The Trust.

At Whiteley Village, The Whiteley Homes Trust provides housing, support and care for about 500 residents, currently aged 67-107. The Trust is an almshouse charity, and for over 100 years has welcomed those of low socioeconomic means.

Acceptance into the village is based on immediate housing need, financial means testing (similar to qualification for social housing), health and on connections within the local area. Some of the larger challenges faced relate to:

- Being custodians of 225 acres of land on which The Trust are unable to build more homes
- Owning over 250 Grade II listed buildings
- The population of the village getting older and with increasingly complex care needs
- Staff retention and recruitment
- Reducing state support for our residents

The key points I wish to pick up from the case studies presented, and based on the situation at Whiteley are:

1. The role of the family in providing care and support for their relative
2. The financing of care

### *The Role of the Family*

As would be expected, Whiteley Village residents vary in terms of their family. Many have children, grandchildren and great-grandchildren, some don't. Some have family living nearby, many don't. Some have kind and supportive families, some don't. One mentality observed within some families of residents is resulting from the perceived care and support provided to residents by the Village signalling to families that they can step back. There is a sense that "Mum's at Whiteley, I therefore don't need to worry or do anything for her". The Village in some way must fill this gap, and this is done through friends and neighbours within the village, volunteers, and paid care and support staff.

When care needs become greater, it is often Trust staff and volunteers who liaise with social and health services, who complete paperwork, and who arrange for transport to medical appointments. One of our greatest wishes is that families do not disengage with the care and support of their relative just because they live within the Whiteley Village community.

That said, and in contradiction, it is completely understandable that many families are unable to or are unsuitable for being involved. Many families live too far away. And many family members have neither the time nor the aptitude for providing the practical or personal care needed. The pressures on families of residents (who are often themselves in low paid jobs and living in social housing) often doesn't allow for them to help. And it would be an incorrect assumption that they are the most suitable or qualified to provide care. A flexible system is needed.

One area of care that perhaps receives insufficient attention for many older people, including residents at Whiteley Village, is psychological and emotional support. Whether this comes from the family or elsewhere will vary between individuals, but there is a need for widening the provision of overall care to include psychological and emotional support. Older people often must make significant adaptations to changing physical health, transition into retirement or into a retirement community, and the loss of close relationships. Additionally, older people are susceptible to mental health difficulties and are carrying with them, often unacknowledged and unresolved, a lifetime of losses, disappointments and lack of control. All these can spill out in older age as unacceptable and difficult behaviours, that makes the provision of care and support services (whether by neighbours, friends, family, volunteers or staff) challenging.

### *The Financing of Care*

Many of the Whiteley Village residents are at the coalface of dealing with reduced state support. Services that are needed, but had also become seen as a right, are being withdrawn or reduced, particularly related to personal and social care. Residents at Whiteley Village are relatively fortunate in being part of a community, and with The Trust's support, to fill these gaps. For example, The Trust pays for physiotherapy, keep fit and body balance classes, and reminiscence therapy. And there is a strong culture of the younger and more healthy residents volunteering to

help the older frailer residents. There is much neighbourly activity and strong friendships formed.

The Trust staff also do much of the negotiating with social services to ensure that where possible, personal care is paid for. In cases where it is not paid for, or insufficiently paid for, the charity fills that gap and families are not asked to contribute. This can become acute in the provision of nursing or residential care, where annual contributions of the charity to make up this funding gap ran to over £100,000 in 2018-19.

Another significant impact on the reducing state support is regarding the recruitment and retention of care and support staff. This is a nation-wide challenge and means that the capacity to meet the not unreasonable desires of residents for continuity of staff, sufficient time with them, regular and timely visits etc cannot always be met. So, who should pay? And how can care and support staff be paid what they deserve? If this was simple to answer, it would have been answered by now. Clearly, in a country that has and believes in a welfare state, the most vulnerable need to be protected and valued, and the elderly of limited means are certainly vulnerable.

### *Conclusion*

It is easy to conclude by saying that there needs to be more state support, and there does. However, perhaps there also needs to be flexibility in the system so that families find it easier to contribute. This means that a daughter (it often does fall into gendered roles) who gives up or reduces her work to support an elderly parent is adequately supported. And it might mean questioning what services older people and their families have a right to expect, and to reframe some service provision from being “needed” to “wanted”.

### **Dagfinn Naden**

Professor at Oslo Metropolitan University. Research areas: Empirical and theoretical research; dignity, suffering, health, confirmation, encounter, nursing as art, hermeneutics, elderly care.

### **Commentary**

#### *Background*

First, I briefly present one important health and care service act and one important regulation within elderly care in Norway, which can serve as information and background perspective for the following comments. In addition to bringing my country perspective, I will view the cases through the lens of dignity to some extent - as an aspect of my disciplinary perspective. The focus in this commentary is on formal caregivers and authorities.

In Norway health care services are free of charge. Municipal health and care services are regulated by law through the Health and Care Services Act (2011).

The objectives of the Act are, in particular. to:

1. prevent, treat and facilitate to cope with disease, injury, suffering and disabilities.
2. promote social security, better living conditions for the disadvantaged, contribute to equal worth and gender equality and prevent social problems.
3. ensure that each individual has the opportunity to live and dwell independently and to have an active, meaningful existence in fellowship with others.
4. ensure the quality and equality of the services offered.
5. ensure coordination and that the services offered are available to patients and health care users and ensure that the services offered are adapted to the individual's needs.
6. ensure that the services offered are organized with respect to the individual's integrity and dignity
7. contribute to the best possible use of resources.

In 2011 the regulation 'The Dignity Guarantee' entered into force in Norway. It states that if you receive municipal elderly care services, you shall be provided a dignified service adapted to fit your individual needs, insofar as possible. You have the right of self-determination and should be met with respect for the person you are and your way of life. Health care services are received under the Health Care Act or the Act relating to social services. Such services might be home help services, home nursing care or a place in a nursing home.

The guarantee points to the following:

- That you have the correct living arrangements based on your needs and condition
- That you have a varied diet and customized assistance with meals
- That you have the most normal life possible, with a regular routine and the ability to be out and about, as well as the help you need with personal hygiene
- That you are given the chance to talk with someone about essential questions of existence
- That you have palliative treatment and a dignified death
- That you retain or improve your ability to function in daily life
- That you receive adequate follow-up from a doctor or other staff
- That you have a private room if you are living in a health care institution.

From an overall point of view, we observe both dignity and indignity in the cases, from individual persons and from authorities. People are acting differently according to responsibility, be it professional or by family caregivers.

Most often when deprivation of dignity emerges, old persons' bodies are failing, so also in Harry's case. In combination with dementia, he is also in great need of help with daily activities. We observe that both Harry and Alice are humiliated because of the manner in which the care assistant from the authorities are treating them (strides straight into the bedroom without as much as saying hello, and by her attitude encountering Harry). It seems like the person from the Council has little or no knowledge of how to behave and care for persons with dementia. This case, as do

the others, deals with several ethical concerns. There is a parallel in the home care case study from China, where a care worker from a major hospital was hired to help Mr. Wu, who is 94 years old and has been diagnosed with a malignant tumor of the prostate with bone marrow metastasis and became bedbound and incontinent after a while. The assistance from the care worker comes in addition to the care offered by his children. This care worker also humiliated the sick patient and indirectly his family members, performing inappropriate care for him at night, not watching him and following him to the toilet, and tying his hands to the bed. The care worker is physically present but at the same time absent.

Metaphorically, we may say that there is an overall theme of abandonment in the cases. To be abandoned touches something deeply human since human beings are dependent on each other. To be deprived of togetherness with other human beings can leave the individual in loneliness and despair. This may be experienced even worse when the individual is old, has a physical or psychological disability or has dementia.

It seems like the care assistant abandons Alice and Harry in the very first meeting with them, not physically, but mentally, and therefore it might be more correct to consider this 'performance' as 'abandonment in advance', actually before entering the arena.

Seeing the other person is important in all caring, and Levinas (1996) states that by seeing another person, one is responsible for him and for his responsibility. We cannot refuse the responsibility for the person. Being abandoned when in suffering is interpreted as the opposite of the meaning of responsibility, in Levinas' perspective. His thinking (Kemp 1992) is driven by the notion of infinite suffering reaching further than oneself, to the other as an ethical authority. We must open ourselves for the other and acknowledge that the other has a right that we have to come to grips with against our own egoism (Kemp 1992). In the light of the above, individuals who live at home needing home help services and nursing care have a right that has to be acknowledged and respected. Abandonment and its nuances of indignity in care might be viewed as a wrongful discharge of power.

In transferred meaning, we may consider that the authorities have abandoned their citizens, Harry and Alice, in not providing care through qualified personnel. It is the public sector's responsibility to provide safe treatment. The time of the visits from the authorities, which is early in the morning, does not suit Harry either, because he has always been late to bed. Seen from a Norwegian perspective, the authorities' routines for visiting the home of Harry would clash with two paragraphs in The Health and Care Services Act, which state that the services offered are available to patients and health care users and ensure that the services offered are adapted to the individual's needs. The services should also be organized with respect to the individual's integrity and dignity. The authority's routines would also clash with the dignity guarantee, which states that individuals should have the correct living arrangements based on their needs and condition.

Although the roles and overall responsibilities seem to be more unclear in the Chinese case, there are also similarities with regard to responsibility in the UK case. The management station of the major hospital in China ought to be responsible giving safe and appropriate nursing care to people living at home, even though the care worker himself decided the wage, which was higher than the market price. The care worker did not live up to the responsibility given to him. His role was to provide good and appropriate care to Mr. Wu. By tying his hands to the bed, he instead deprived his dignity.

There is also a humiliation of Alice and Harry caused by the authorities concerned, when the yearly assessment turned out in withdrawal of care in mornings for Harry. This seems to be due to uninformed knowledge or economical concerns. A person with dementia who is assessed not to be mobile enough to get downstairs without assistance would probably not be able to manage it better one year later, because of the development of the disease with its consequences for both mind and body. The Chinese case study of residential care is an example of excellent care from healthcare personnel, led by the experienced Head Nurse. The head nurse has really interest in the patient, Mrs. Wang. She communicates with Mrs. Wang's children to ensure appropriate information to do the best for her, for example taking the initiative to install a TV for her and offering the fruits she likes. The nurse shows a proactive attitude and does not give up when meeting challenges. It was her profit that a specialized ward for patients with dementia was established at the Institute. She is responsible, knowledgeable and dedicated to her work, and preserve the patient's dignity without talking about it.

The impression is somewhat different when it comes to the UK case study of residential care. The staff seems almost 'absent' except when it comes to resident Greta's relationship with a fellow resident, and when family caregivers inform staff about what their dear ones wish and like. We might interpret the reaction of staff as not wanting to be 'disturbed' by family caregivers. An exception is the voice of a Polish nurse, who thinks it is positive that the family informs the staff about the person's habits and desires, because the family knows them best. On behalf of the patients, she raises the voice. This is one way to fight for the patients' dignity.

### *The future*

When it comes to the quality of health care services, we find that there is both good and bad care. One future perspective is to focus on and to find out more about why older adults are exposed to unworthy care.

The Universal Declaration of Human Rights, Article 1, states: All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood. We might look at this statement being a compass and a headlamp on the road we all have to go for the endeavor of an even better care of the older adults, be it leaders of various health care services, researchers, educators, health authorities or health care providers.

### **Ross Upshur**

Dr. Ross Upshur is currently the Dalla Lana Chair in Clinical Public Health and Head of the Division of Clinical Public Health at the Dalla Lana School of Public Health, Scientific Director, Bridgepoint Collaboratory for Research and Innovation and Associate Director of the Lunenfeld Tanenbaum Research Institute, Sinai Health System. At the University of Toronto, he is a Professor in the Dalla Lana School of Public Health and the Department of Family and Community Medicine, affiliate member of the Institute for the History and Philosophy of Science and Technology and Adjunct Senior Scientist at the Institute for Clinical Evaluative Sciences.

### **Commentary**

The last century has witnessed remarkable growth in the human population. By 2050 the total population of the earth is expected to exceed 9 billion. When one looks globally at the distribution of this population one will see familiar patterns. Low and middle income countries tend to have populations shaped like the traditional population pyramid, with a large number of children and diminishing numbers through the life course. Higher income countries tend to have more bar bell shaped population pyramids with increases in the number of older adults. In some jurisdictions like Canada the fastest growing segment of the population is the oldest old, those greater than 80 years. However, in all jurisdictions around the world, the population of older adults is growing. Part of the explanation for the extension of lifespan relates to successful public health interventions such as improvement in child and maternal health, effective prevention such as mass vaccination and better clinical health care. Some have referred to this as the rectangularization of mortality.

The successful rectangularization of mortality has not been matched by a similar effect with respect to morbidity. The narrative of the early 21<sup>st</sup> Century is one of increasing chronic disease and multi-morbidity, the accumulation of more than one concurrent chronic condition, in particular. It has been claimed that multi-morbidity is the rule not the exception, and this is borne out by several epidemiological studies conducted around the world. Although not inevitable, the vast burden of multi-morbidity is found in the late life course.

Research indicates that as people age they acquire increasing morbidity burdens. These can often be managed successfully and people can live quite well with high morbidity burden. However, for the most part decline is inevitable at some stage and with decline comes a greater need for systems of assistance and care. Quite frankly, few societies have future proofed health and social systems or prepared families and communities for effective provision of the full spectrum of services to meet the needs requisite for compassionate patient and family centred care in the community. We still organise healthcare, train health care providers, and organize clinical services along the imperative and logic of single diseases, usually focused on organ systems and body parts.

That the demographics of the morbidity transition have not been better anticipated and prepared for by policy makers is a shock to those who seek care from existing health and social care systems. The cases for discussion illustrate the strains, shortcomings and inadequacies of care for increasingly vulnerable older adults in China in the UK. Sadly, the geography could easily be substituted in the events described for any jurisdiction I know. These cases would not, in any way, be out of place in Toronto. In fact my clinical research experience indicates the same, if not worse, fragmentation of care, caregiver burnout and patient disappointment in Canada.

These cases reflect the typical trajectory that I have studied in primary care in Canada. There is a familiar ring to the cases. The narrative has the following structure: An older adult, or a couple, is managing well. They have been retired for some time, accumulated a few health challenges but managed, for the most part, successfully and for the most part, independently. They may, or may not, have sufficient financial means to get by.

Things generally go well until they age into the late 70s or early 80s when one of the couple, or indeed both, are diagnosed with a serious illness or begin to show signs of cognitive and functional decline. One or the other of the spouses may pass away with attendant issues related to grief and bereavement. The family is usually dispersed and often there is one adult child nearby. This adult child, usually but not inevitably a daughter, assumes the primary role of arranging care and providing support. The primary caregiver either has professional responsibilities or her own family to care for. Everyone copes as best as they can until something happens. Care needs to be reorganized or integrated and slowly but surely care demands exceed the capacity of the spouse and the family. Extended caregiver support is sought from public or private sources and these often prove insufficient. Finally, alternative living arrangements are considered only to be found unsatisfactory to all. Relationships are considerably strained, resources depleted.

Many commentators have reflected upon missed opportunities to reorient care and resources to both support families and to promote aging in place and death at home. Research indicates that this is the preferred option for most people. Many families make significant sacrifices and perform near supererogatory acts to assist loved ones achieve this goal. There is much more I could say about these cases and suspect I will have the opportunity to provide more perspectives during the three days. However this much is clear. The arc of care of the late life course is well documented. Transition points and changes in status are predictable and should be anticipated. There seems to be an inability to accept this and design communities and develop policies that recognize this predictable trajectory. This has made navigating the late life course much more challenging, exhausting and difficult than it needs to be. Families often willingly take the responsibility of care. Indeed they often do not see their work as caregiving at all. Caregiving can be wonderfully rewarding and enriching, but is also arduous, taxing and as family members become more and more dependent, exhausting and ultimately unsustainable. Agency support, whether

public or private, often fails to appreciate or care about the quotidian nuances that give shape to a meaningful life. Issues around bedtime, feeding time and intimacy tend to fall prey to the mandates and dictates of systems rather than uphold, respect and celebrate the particularities of how a person has grown to live their lives. Care homes are increasingly industrial and commercial and unwilling to accept residents who pose heavy care burdens.

This spectre has been predicted since the early 80s for high income nations and by 2050 there will be an estimated 430 million people in China over the age of 60. In the coming decades there will be more and more older adults, the vast majority of whom will have stories like the four cases we have for discussion. There is nothing exceptional about any of these cases. Their very ordinariness and typicality is what is so concerning.

Even with recent attention to advance care planning and integrated systems, we still see willful blindness. We continue to have health care providers tell patients to call “if something changes” rather than planning for the inevitable changes to come. If we imagine how we respond to the needs of our oldest and most vulnerable members of the community and the policies and practices in place to respond to their needs as mirrors of our values and priorities then we have seemingly systematic indifference and near cruelty to reflect upon. I've often referred to how we've organized our health care systems as brutal throughput meat machines under the guise of beneficence. There is much that we can do to improve and integrate social policy and healthcare, with less emphasis on health care and more emphasis on social support and maintaining older adults safe and at home.

We do not know how the four cases end as we do not have completion of the stories until death. We are left wondering how these families managed until the inevitable death of the protagonist. In many ways Harry and Alice, Wu Haichuan and Huang Ning, Greta Smith and Wang Yuying are fortunate to have supportive and loving families and rich networks of relationships. There was great strength and resourcefulness evident in each of the stories. Not all older adults are as fortunate, and we are now faced with even greater challenges in addressing loneliness and isolation in this population. Let us hope that policies and practices change and are adequate to the task.

**Michael Gusmano**

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**Commentary**

Should the cost of long-term care be a public or private responsibility? In all four cases developed for this project, the cost of long-term is a factor. In the first case, the Surrey Council's decision to reassess Harry and reduce the support for which he is eligible places greater strain on his wife Alice and their children. In the second

case, the cost of hiring Mr. Li exceeds what Mr. Wu can afford and his three sisters agree to help pay for the care. In the third case, before her mother, Grace, needed to enter a care home, her daughter Maria gave up her job to provide care at home. After Grace moved into the care home, one of the concerns expressed by her son David was the cost of her care. In the fourth case, half of Mrs. Wang's nursing costs were paid for by her children. The cost of care does not appear to be an overwhelming burden for the people in every case, but it raises the question of how this type of care should be financed.

There is broad consensus among most countries in the world that health care services should be financed collectively. The U.S. stands out as the only country in the Organisation for Economic Cooperation and Development (OECD) without a commitment to universal health coverage. The U.K has relied on the National Health Service as the main source of care for its citizens since 1948. The commitment to public financing in China has varied over time, but in 2009 the country expanded health insurance coverage for its citizens with a goal of achieving universal health coverage (UHC).<sup>i</sup>

When it comes to long-term care, particularly community based long-term care, however, this is not the case. In many countries, including many wealthy countries, financing for long-term care is far more limited and is often means tested, rather than based on social insurance principles. Germany, Japan and the Netherlands are rare exceptions.

**What is the rationale for using social insurance principles to finance pensions and health care?** There are several standard reasons for using social insurance principles, which call for spreading risk across an entire population through the tax system, for financing certain types of goods.<sup>ii</sup> One is to address the problem of adverse selection. If the only people who will seek private insurance to protect against a risk are those at greatest risk for needing the service, the price of private insurance rapidly becomes unaffordable.

A second rationale for social insurance is the existence of unwarranted optimism. When people underestimate their risk of needing a good, they fail to plan appropriately for future needs. Research on optimism bias demonstrates that, in many domains, people overestimate the probability of positive events and underestimate the probability of negative events.<sup>iii</sup> This is why people frequently underestimate the odds that they will get sick or develop a disabling condition.

Third, social insurance principles are considered appropriate if the person in need of assistance should not be blamed for their need. Although individual decisions and behavior certainly contribute to poor health, it is the result of a complex array of factors, many of which are outside the control of an individual. Similarly, whether people have savings that are sufficient to cover expenses in retirement depends, not only on whether they have worked hard and made responsible choices throughout life, but on large economic forces for which individuals have no responsibility. These

rationales for pooling risks across the life course are broadly accepted when it comes to health care and pensions but are rarely invoked for long-term care.

**Why do we use different principles to finance social and health care?** The failure to use social insurance principles to finance long-term care in most countries does not reflect fundamental differences between social care and health care. All of the justifications for using social insurance principles to finance health care and pensions apply to long-term care.<sup>iv</sup> Regardless, most countries continue to shift risks for this care to families.

The failure to pool risks for long-term care services is driven, in part, by the fact that women provide most of it. As a result, societies across the world have discounted the value of such care and assume it is something that ought to be provided for 'free' by women. In this context, growing opportunities for women to pursue educational and career goals is framed as a 'problem' in the face of population aging.

The cases developed for this project illustrate the sorts of injustice that arise when we place responsibility for these predictable needs to individuals and families. Women take on most of the direct responsibility for the care of older parents and spouses. In some cases, this may force them to leave the workforce, but even if they do not leave their jobs, they are just as likely to add the burden of caregiving on to their other responsibilities.<sup>v</sup> The strain of taking on all of this extra work can lead to health problems. Caregiving is associated with increased stress and medication use, lost time at work, interruptions in other social relationships, misuse of alcohol or prescription drugs, incidence of coronary heart disease, and depression.<sup>vi</sup>

**The limits and value of public financing:** It is important to note that public financing is not a substitute for family caregiving. In most cases, when families receive formal care services, it complements, rather than substitutes, for family care. Moreover, providing public funding for long-term care services does not resolve all of the ethical issues invoked by the cases in this project. For example, it does not resolve the question of what obligations family members have to provide care to each other. As Jennings and colleagues explained more than 20 years ago, providing greater social support, including public financing for long-term care, does not resolve 'the moral expectations family caregivers quite properly impose upon themselves, and the cultural ideal of what it means to be a good person in a family role.'<sup>vii</sup> It can, however, minimize some of the injustice that shifting the financial burden of care onto families creates.

### **Dave Archard**

David Archard is Emeritus Professor of Philosophy at Queen's University Belfast and Chair of the Nuffield Council of Bioethics. Educated at Oxford and London he has taught at the Universities of Ulster, St Andrews and Lancaster. He has published widely in applied ethics, legal and political philosophy, especially on the topic of children, parents and the family. He is Vice President of the Society for Applied Philosophy.

## Commentary

### Our Responsibilities to the Old

Here are the relevant ethical principles that apply to our care for the old within society and some thoughts about how the case studies illustrate the application of those principles.

Most people think that everyone, irrespective of their age, is owed a decent life. Most also probably think that this is owed equally to all in society even if what enables each to lead a decent life is not the same across all ages. For instance, the greatest per capita expenditures of health and social care are at the beginning and end of lives.

However, for philosophers it is contentious whether we should pay more for the old to ensure that they have a decent life. Thus, there is the 'fair innings' view that we should ensure that everyone has an opportunity to live to a certain age, but that, thereafter, individuals have a weaker claim, compared with those yet to reach that age, to the provision of care.<sup>1</sup> Others remain clear that the provision of care should not be age-sensitive.<sup>2</sup> Still others think that fairness demands priority being given to the onset of adulthood and maturity.<sup>3</sup>

The foregoing leaves open the question of who should discharge the duty of care for the old and, in particular, the extent of the obligation owed by the family to their older members. At one extreme is a libertarian view, perhaps best instantiated in the laws and policies of the United States, that individuals alone bear the responsibility for their care in old age, and thus should make provision – for instance through appropriate insurance policies – for such care. Other societies have a mixed model in which the responsibility for the care of the old is properly divided between the state and the family. It is worth noting that organizations in civil society and the community can also play a role (as with *Age UK* in scenario 1). The precise division of responsibilities will vary and all the scenarios provide dramatic illustration of how restrictions in state funding and, correlatively, the limitations of privately funded alternatives make a huge difference to what can be offered to the old.

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<sup>1</sup> A Williams, 'Intergenerational equity: an exploration of the 'fair innings' argument,' *Health Economics* (1997) 6(2):117-32

<sup>2</sup> John Harris, 'The Age-Indifference Principle and Equality,' *Cambridge Quarterly of Healthcare Ethics* (2005), 14: 93–99

<sup>3</sup> Norman Daniels, 'The prudential life-span account of justice across generations.' In *Justice and Justification: Reflective Equilibrium in Theory and Practice* (Cambridge Studies in Philosophy and Public Policy, Cambridge University Press, 1996): 257-283

Care for the elderly can usefully be compared with the provision of childcare where we think that parents should discharge the primary duty of looking after their children (and do so to a certain threshold of decent care) yet not do so unaided. In effect the state assists parents with that duty. And equally the quality of care depends on the level (and distribution) of state provision and alternatives in a private market or within the community.

Key remaining ethical questions which the scenarios neatly illustrate are *why* family members should look after their elders, the *scope* or extent of that responsibility, and the *form* it should take.

In respect of '*why*' everyone agrees that grown-up children owe *something* to their parents. All the children in the scenarios clearly accept this. There is disagreement in the theoretical literature about why there should be what are called 'special obligations' in this instance.<sup>4</sup> An appeal to gratitude (for our upbringing) faces the difficulties of explaining why we should repay a debt we did not choose and how we deal with the problem of gradating the debt of gratitude in terms of how much was done for one. Some think that there are unchosen 'role' responsibilities, those that simply come with occupancy of a given role, in this case that of 'being the child of'. It would be interesting to see whether the Chinese view our duties to elders, deriving from Confucian ideas, in similar terms. In scenario 3 p.6, Maria feels 'guilt' at the care her mother is receiving but this is because of a broken promise (not to let her be in a home).

In respect of the '*extent*' of one's duty the question of how much is owed to parents is clearly viewed differently by the children in the scenarios with some being critical of their siblings for not doing enough. However, what we owe must at least take into account other obligations we have, most obviously to our own children. In scenario 1 p.3 Alice makes this clear to her daughter: 'You've got your own life to lead, and your own children to take care of'. Yet clearly this disfavors the single or widowed sibling with little or no other duties. Or it imposes unacceptable burdens on family members with existing commitments and perhaps, as the scenarios illustrate, at a geographical distance. In scenario 2 Wu Qian as 'a widow' who 'lives near her parents' is pressurised to take on the major caring role.

Talk about what one can be asked to do given work commitments (as with Wu xin in scenario 2 p. 4) should not be dismissed - and not simply because employment serves the end of maintaining one's own family. This is because what we do at work helps in significant ways to defines our identity and purpose in life. However, it is notable that it is the male children in the scenarios who lay claim to the importance (and irreplaceable commitments) of work, leaving female siblings to take on immediate care.

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<sup>4</sup> Diane Jeske, 'Special Obligations,' *Stanford Encyclopedia of Philosophy*

<https://plato.stanford.edu/entries/special-obligations/>

The question of the *form* of care that is owed to one's elderly parents is distinct from that of the extent of one's duty. It seems morally worrying if a grown-up child believes that a monetary payment for care of his or her parents is appropriate. There may be exceptions and, interestingly, there seems to be a view that if can only offer money then it should be greater than a simple pro rata division would indicate. Thus, Mrs Wang's son in scenario 4 p. 9 lives abroad and cannot in consequence provide face to face care. His willingness as a result to pay 'the greater part of the expenses' of care seems appropriate and fair. Similarly, Wu xin in scenario 2 p.5 who has less time for caring for his parents than his siblings is willing to bear the main cost of nursing care for his father.

The demand that children offer personal care seems to rest on the particular bond that exists between family members (only a child can be 'the small cotton-padded jacket' (scenario 2 p.4)) and the special knowledge family members have of one another. Beata's comments in scenario 3 p. 7 about the importance of shared family memories to personal identity is, in this context, nicely expressed. Equally there is the fact that some forms of care provided by strangers are felt by the elder as a violation of their privacy and as unwanted intrusion (scenario 4 p. 9). In scenario 1 p.2 Alice feels 'shame' that her husband's carer –a stranger to him – and not her is providing intimate, personal help.

Yet all the scenarios show that some needed forms of care – medical and psychiatric, particularly – would be beyond the capabilities of family members and demand professional assistance.

A final thought: much is made about the differences between European and Chinese ethical attitudes, especially when it comes to something like the family and the duties of its members. Yet the scenarios display a revealing commonality both of concern for the old and in identifying the moral sensibilities of family members in caring for elderly parents.

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<sup>i</sup> Wang, H., M.K. Gusmano and Q. Cao. 2010. Review and Evaluation of Community Health Organization Policy in China: Will the Priority of New Healthcare Reform in China Succeed? *Health Policy* doi:10.1016/j.healthpol.2010.07.003.

<sup>ii</sup> Marmor, T.R., J.L. Mashaw, and P.L. Harvey. 1992. *America's Misunderstood Welfare State: Persistent Myths, Enduring Realities*. New York: Basic Books.

<sup>iii</sup> Sharot, Tali. 2011. The Optimism Bias. *Current Biology*. 21(23): R941-R945.

<sup>iv</sup> Gusmano, M.K. and I. Grafova. 2018. Financing Long-Term Care. *American Affairs*. Fall: 3-11.

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<sup>v</sup> Pavalko, Eliza K. and Julie E. Artis. 1997. Women's Caregiving and Paid Work: Causal Relationships in Late Midlife. *Journal of Gerontology: Social Sciences* 52B(4): 170-179.

<sup>vi</sup> Arno, P, D. Viola, and M. Gusmano. 2010. The Caregiving Workforce in the United States. Presented at the London School of Economics, September 9.

<sup>vii</sup> Jennings, B., D. Callahan, and A.L. Caplan. 1988. Ethical Challenges of Chronic Illness. *The Hastings Center Report*. 18(1): 1-16.

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## 7. FEEDBACK FROM PUBLIC ENGAGEMENT EVENTS

On the evening of Day 2 of the networking event we arranged an immersive theatre performance by the Entelechy Theatre Company. The 'actors' were older adults who were in beds or on chairs and told stories that related to aspects of social isolation. The 'audience' then mingled around the 'actors' and had conversations regarding their experiences and stories. Photographs, taken during the event, are testimony to the success of the event in stimulating conversations and public engagement. The theatre event was followed by a panel discussion responding to the question: Who is responsible for the care of isolated older adults?



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Public Engagement Events: Entelechy Theatre Group & Panel Discussion 21<sup>st</sup> June



We received email feedback from some of these who participated as below:

It made me feel sad because the man I spoke to seemed to have come from a very poor place and he was in need of help and support and no one wanted to help. He wanted a job, but people didn't stop and give him time to explain what he needed – they just saw him as someone in the street and walked past him. After I saw it I wanted to raise awareness of people who are in a similar situation, especially migrants from other countries and others who don't have as much as we do.

I was interested in the Chinese speaker's comments about older people not being so well looked after, in spite of China's reputation for this. I am finding it hard to remember the exact discussion, but it worries me that at meetings like this we agree to try and change things but it doesn't seem to happen. I feel the Government 'gets in the way' because it doesn't take action and sometimes seems to think that nothing needs to change ([Luke, resident in learning disabilities' community](#)).

[...] I was struck by the comparison of how adults approached the performers with a sense of wanting to 'fix' the isolation whereas my 9 and 11 year old children just wanted to talk to them about their lives ('who is that photo of? Did you love them? When did you last see them?' Etc).

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As a family we spend a lot of time in a care home for older people and my children feel very comfortable starting conversations and games with older people which may not be true for all children. But the lasting impact for me was that we need more intergenerational interventions for isolated older people. I particularly liked the Green Party representative who promoted an 'I will if you will' approach to improving care. My children also found his talk inspirational. ([Anna, mother of 3 children who attended the event](#)).

Thank you for inviting me to such a mind-blowing event last Friday. Please find below its effect on me as a person and a professional:

The day's event took me years down the memory lane, as an Elderly Care Practitioner in one of the London Boroughs and someone from an Extended Family. Although I was physically at GSA, walking round each 'patient/resident' took me miles away in deep thoughts/reflection. It reinforced my long held belief that it is about time someone spoke up for the Elderly in every society, country and across the nations of the world.

The isolation, abuse and neglect must stop, the mugging of the Elderly even in the 'safety' of their homes, on the street, every and anywhere has to stop. The Elderly deserve better care, they deserve our presence, deserve to receive, having given so much. Their wisdom is invaluable and needs to be nurtured and harvested not wasted. I have always had a passion for the Elderly in the society. The neglect/isolation is not limited to the UK but worldwide. Even in cultures where children are the responsibility of their parents and in old age parents the responsibility of their children, this is no longer the case. There is now much more of a culture of dependence in perpetuity from those who should be supporting the Elderly as they age. 'Adopt a Gran' is an initiative that has been on my mind over the years. There are adoption programmes for Children and I feel it is about time we had more for the Elderly. I look forward to attending other similar events ([Ihinosen, Nurse Educator](#))

Charlie felt a little nervous walking into the auditorium and seeing the beds, a bit worried about what might be going to happen because it brought back memories of seeing close family in hospital. However, it made Charlie happy seeing the performance, talking to the performers and finding out about their lives. She liked connecting with new and different people from the ones she usually sees. She liked the fact that it was so unusual compared with what she would normally be doing on a Friday night – at home watching TV or having a takeaway with other people at The Grange. Sometimes the conversation was a bit difficult to follow, but overall it was interesting. The man from the Green Party was most interesting to listen to, and you could talk to him more naturally ([Eloise, CEO learning disabilities community on behalf of resident, Charlie](#))

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Thank you for including me in the morning and evening sessions. It was fascinating hearing about the approach to elder care in other countries and realising how similar it is to the UK approach. There really does not seem to be a good solution for isolated elder care at present.

It was so unexpected and was a very powerful message on the lives of elderly people around us and the problems they face. Talking to them illustrated so clearly how their lives could be enhanced if they could share their concerns with people who have time to listen and advise.

What I found interesting was the opportunity to hear the opinions of experts in different fields of elder care on issues that concern us all ([Alison, Service User Group and Older Adult](#)).

It's a great honour for me to participate in this immersive theatrical performance for the first time. However, there may be a small problem. Every time we change the scene to a different case, we need to re-ask them some basic information, otherwise the story will be fragmented and strange. If they have some basic information around, it might save them a lot of time.

One of the main things I gained from the performance was that it made me more intuitively understand about the different levels of elderly care and care needs through different stories, including physical, psychological and social adaptability. We need to pay more attention to the psychological and social participation problems of the elderly, not only the disease problems of the elderly. The problems of depression, loneliness and social isolation among the elderly cannot be ignored in the practice of elder care.

The panel discussion can brought us different perspectives on elderly care, among which many issues were worth our in-depth consideration. This was worth learning and imitating in the following qualitative research. It's worth mentioning that I was deeply impressed by the age prejudice and discrimination against the elderly. As an experienced group, the elderly still have the right to continue to receive work, education and other social participation. We cannot deprive them of their rights and opportunities to realize their self-worth because of their age or physical ability ([Steven, PhD Student from China](#)).

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[...] thank you for arranging such a stimulating event and for extending the invite out to homes such as ours. For me, this was a very novel approach to engaging an audience in a most important issue and my wife and I came away uplifted by the experience. I am struggling to find the right way of describing the experience. I think I said to you immediately afterwards that it was both enjoyable and disconcerting at the same time. I remember the first thing that 'Iris' asked me was to help her with her medication and I thought, help, I'm going to do the wrong thing here! For a period of time I was trying to 'discover' something about the person in the bed before accepting that there was no right or wrong way to interact.

This was a thoroughly authentic experience despite it being a performance – remarkable and I take my hat off to the actors and Director of Enterlechy AC. The consensus view that seemed to be reached was that it will be the small things that people do within their own communities that will cumulatively make the difference (Tim, Care Home Manager).

Impact? Initial shock, slightly nervous, slightly uncomfortable. Very happy to chat with actors, I no problem with the chatting but found it difficult to work out what my role was. I think the impact came from the directors panel discussion and the actors speaking after about how it has bettered their health and well being.

What was interesting? Very strong. Liked all the speakers, all had something positive to say. Sadly no solutions. Might vote Green in future. The importance of inspiring people to bring about a shift in culture. Hope that helps, please keep me in the loop (Matthew, Domiciliary Care Home Manager).

It reinforced my views that isolation is being thought about in a way that is too pigeon-holed. Isolated elders are just 'regular' people with a slightly different mix of challenges from other parts of the community, whether that is awkward teenagers, people with learning disabilities, mums with very young children etc. And often, what works for one so-called 'group' is a solution for everyone. Funding is being wasted if it is simply being channelled into one group or another, and not underpinning a whole-society approach.

I felt the panel were in many ways saying things as new or interesting that those of us working with vulnerable groups had understood and moved on from some time ago. It disturbed me that the solution was considered to be 'more Government funding' by more than one of the panel, which reflects a lack of realism and practicality. I also think that there is a language gap between some of the panel members and those – like me – who are doing the doing at the coal face.

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What was interesting was to understand that this is an international problem, and even places like China which are held in high regard for their attitude to elders generally seems to be struggling.

What made me smile was at the end where the two Grange residents simply swapped numbers with two of the people from the theatre company and made arrangements to stay in touch, share each other's events etc. Somehow, we need to focus on creating these 'touch points' for potentially isolated people and not worry so much about the theory maybe? (Eloise, Chief Executive, learning disabilities' community).

Thanks again for providing such an invaluable opportunity for all my students. It is a ground-breaking event for us, as this is the first time that we interpret for such high level academic conference. We have learnt a lot during these three days, students got real experience and there is still a lot to improve. We are now reflecting on how to improve our training in the future for such type of academic activities (Wang, Lecturer, Languages Department).

I thought the performance was very impactful, mainly because it felt 'real'. I felt slightly awkward in the interactions with the actors, because some of the stories were quite emotional, and I did not know to what extent the actors were drawing on personal experiences, or the experiences of people close to them. It made me a bit afraid to say the wrong thing, and I found it hard choose the 'right' moment to walk away from one person, and go speak to the next. As I was experiencing these feelings, I started realising that this was probably the point of the performance.

When standing around a bed with several people, I almost felt like I was intruding. In real life, I would not have chosen to stand next to a bed if other people were already standing around it, in order to not interrupt their conversation, or overwhelm the person in the bed. Standing in itself also felt strange, because you were looking down on the elderly person. I preferred kneeling (or, in the case of the people sitting in chairs) sitting on the floor, to be level, and able to make good eye contact.

One thing that I also thought was interesting was observing the reactions of other people to the actors, and how they were similar and different to my own. For instance, I was quite hesitant to ask the actors questions about their health status, but some other people were more comfortable to do this.

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The panel discussion was also good. It was great to have such a diverse panel, and some important points were made. It was good to have the input of 'lay people'/service users in the audience. Perhaps it would have been interesting to ask the panel and the audience some more thought-provoking questions in response to the performance. For instance about how one's previous experience influenced one's interaction with the actors. All in all, a great evening, and lots to think about ([Hanna, PhD Student from Netherlands](#)).

I had a really good day on Friday and enjoyed both the conversation café and theatrical performance a lot. One of the main things I gained from the performance was a reminder of what really could make a difference for isolated elders: reciprocal relationships and connection. It was interesting and rewarding to listen to the stories of the actors and it brought to my mind the challenges within nursing of creating the time to sit and listen when there were so many pressures to "do". I was also surprised by the reactions of a number of people in attendance, who I know to be confident, experienced and highly articulate, who said that they felt awkward, a response which I think merits some analysis. One person in attendance asked an actor "What setting is this supposed to be?" which I thought was rather missing the point. Another started offering suggestions in relation the issues raised by an actor which might have been very helpful but, again, I thought the actors might have been more interested in us listening to them and acknowledging the legitimacy of their concerns.

The panel discussion was very interesting and led on from the conversation café very well. There were a number of points I went away and thought about:

- We have a tendency to view elders as an homogenised "other" and deny ageing as a natural part of the lifespan.
- Mutual dependence is a feature of being alive and not limited to the very young, old or disabled.
- There appears to be shame in the acknowledgement of dependence.
- We create dependence and isolation in our marginalisation of older people.
- Isolation is a subjective experience and cannot be assumed to be directly related to proximity of other people including family members.
- We often regard an ageing population as a "problem" and downplay what elders can offer society/individuals
- Volunteering with elders may help not only older people but also those doing the volunteering.
- While elders may be at particular risk of isolation, there are limitations in regarding such isolation as a problem of old age in particular.
- We could waste time and opportunities by waiting for government responses and personal/local action is needed.

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- The arts are an excellent way of promoting connection and helping us understand who we are, where we have come from and envisage the future.
  - Any successful strategy in relation to the isolation of elders will require the building of alliances and multi-agency working.
  - In short I think I left thinking “we are all in this together”

I had attended the recording of a radio interview with Michael Sheen earlier in the week which mainly focused on the social action work he is involved with in his home town of Port Talbot and many of the above points came out there as well ([Jane, Retired Nurse Educator](#)).

## 8. CAFÉ CONVERSATION THEMES

In the morning of Day 2 of the networking event, we brought together a wider group to discuss each of the ‘3 P’s’ (philosophy, policy and practice). In addition to the group of international experts, we invited older people, service users and staff members from the School of Health Sciences. The Café Conversation model involved a facilitator at each of 3 tables enabling each member of one of three mixed groups of international experts, service users and practitioners engaging in conversation. Each group rotated every 45 minutes, so they had an opportunity to engage with all of the ‘3 P’s – Policy, Practice and Philosophy. Below is a summary of the themes.

### POLICY

- **Strategic approaches to policy development**
  - A need for much more user-sensitive policy-making so that older people and their carers can determine deficiencies and what might work
  - “No numbers without stories, no stories without numbers” – a role for evidence and advocacy. Policy makers must become comfortable in bringing different kinds of evidence to the table
  - Policy-making should move beyond splits that older people don’t make themselves (between health/social and care/end of life care). We need joined up thinking and an approach to “whole ageing” policy
    - New policy relationships and connections between statutory, voluntary and third sector organisations will be key here
  - Transportation, affordable housing and the built environment are hugely important for older adults. Societal investments in infrastructure must underpin care policy
    - Building of healthy cities; policies to address loneliness that are tailored to local settings (these are typically well-received by older people); creation of new social spaces for older people
    - New forms of awareness and training: does a bus driver know how to relate to a person with dementia so that a new service can actually be useful and experienced positively?

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- Also, don't lose sight of inequities and inequalities between older people and their caregivers: some older people are more disadvantaged than others. One size will definitely not fit all. There will be ethnic and cultural dimensions here as well. There will also be geographical differences (particularly in China between urban and rural areas)
  - Policy-making concerning older people and their care needs to focus on communities in which older people live – the family, the networks, the ecology of carers – not just the older person or family caregiver as isolated older person.
    - A role here for social care prescribing?
  - Continuity of care across care transitions
  - Need to get beyond the ideology of altruistic nice people who need policy-makers to support them. Instead we should move to an impartial but imaginative needs-focused approach
    - Rewarding nice people leads to inadvertent punishment: e.g. people lose out when they devote time, at their own cost, to caregiving for loved ones
    - Make use and expand the WHO's "Making Fair Choices" framework, which seeks to identify basic needs, figure out who has these needs, and then guide the development of services accordingly. Don't leap to higher-level services first (and don't be biased towards those with political power or who can shout the loudest)
  - Sustainability is important: things might sound promising but not be sustainable when rolled out
  - **Innovative policies**
    - The role of health connectors: people with local knowledge and who can help to personalise the delivery of care to the local community (e.g. the postmaster)
    - Coach for Care – Hospice Movement: passing on caregiving knowledge from ex-carers to current ones
    - New ways of living well together
      - Funding for pets
      - Dutch model of shared living spaces for oldies and students
      - A European-inspired 'national social service' by young people – beyond just relying on altruism and volunteering
    - Universal care provision, modelled on universal health provision
      - The meeting of the most basic care needs for all
      - Beyond the medical: focused on low level social and interpersonal requirements
      - Away from 'the place of care' to 'what are your care needs'
    - Learning from Canada:

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- Linking care policy for older adults with public health policy to promote as prevention-focused approach – also allows care needs to be linked to transport, housing etc.
  - We need harmonisation of social policy-making in robust approaches to policy development for older adults
  - Technology-focused approaches to new interventions
    - 5G and the Internet of Things – works both to better connect older people and also to re-enable in everyday tasks and meaningful experiences around the home
  - The instigation of planning-focused initiatives:
    - We have advanced care planning for people in hospital settings with illnesses close to the end of life. How we can promote social dialogue about planning for the future across all aspects of our lives as we age?
  - **Policy-making across borders**
    - Need for systematic policy analysis
      - In a given country, what policies help people care for each other? What policies impede care? How should a comprehensive policy support care?
    - Migration in care work needs to come with reform to access to services for immigrants
      - Includes universal access to health care for migrant workers
    - China's 1 child policy: government is having to respond with innovative schemes (particularly around insurance) because of a looming crisis
      - Slowly catching up after focusing so heavily on economic policy and reforms, however because of the strong economic focus in government discourse, the current policy priorities remain too heavily focused on financing and insurance issues in care
  - **Current challenges in policy-making processes**
    - Care policies are multiple and often disconnected: no joined up policy making between departments and organisations responsible for co-ordinating and delivering social policy
    - Policy-making is motivated by money and evidence-base (does the policy work). Values get less of a hearing
    - The research-policy making gap
    - Beyond short-termism: the sticking plaster approach that does not go beyond thinking about the allocation of money
    - Too much focus on health – the missing focus on healthy older people and their needs as well as a bias towards health care needs and not other aspects of older people's lives that make them go well

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- Policies remain orientated towards requiring families to support / pay for care for older people, but social policy is not enabling in the sense that it does not allow families to take on this role without being penalised economically or in other aspects of their lives (e.g. work)
  - Addressing the NIMBY problem: we need more affordable housing that can support older people; people don't want new houses to be built near them.

## **PRACTICE**

### **What 'practice' means?**

- Practice is how you put into effect, in the best way possible, what the policy has dictated
- A case of trying to capture from people who have been through caring what they think is good practice
- All I ever come across are horror stories, whether it's at home or whether it's in old age home or in hospital. There are a lot of good things out there that people don't talk about
- Practice is a translation of what we ask people to do, and what they do, and the disconnect is frightening
- What people do and why they do what they do
- It's muddling through incident by incident, day by day

### **Inequalities in care provision**

- Variation in the quality of care
- Imbalance between urban and rural areas care provision in China
- Older people in rural areas have higher long-term care needs
- Children to go work in large cities
- Insufficient resources to cover care requirements of older people – Chinese society is ageing very fast and the economy is not so well developed
- One child policy in China has a significant impact – burden of care

### **Challenges in care**

- Lack of planning for care emergencies – responsibilities of individuals?
- Urgent care situation, being called out at 3am, and families shocked
- Children of elders may be old themselves
- Geographical separation of parents and children
- Employers not always sympathetic to people taking time off to care for older people
- Labour shortage is a big problem in Japan and the retirement age has been extended to 70
- Challenges in families, for example, what counts as a 'fair share' for a daughter-in-law in a family
- Physical and financial burden on families relating to care of older people

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- An example that springs to mind is discharge home with no support in place, followed by readmission
  - When families and care-givers disagree about good care, for example, using an incontinence pad versus not (when care-recipient wishes not to use one and is incontinent)
  - Where are you going to get the nurses from? Can we/should we encourage those who have retired early to work in care?
  - The role of gender in care – perpetuating gender inequalities
  - What are the implications of not remunerating women adequately for care work?

### **Moral emotions**

- A lot of guilt, a lot of anxiety
- Difficulty fulfilling responsibilities to older parents leads to a lot of guilt
- Lack of ethical care, due to uneducated care-givers, can lead to humiliation of elders
- Practical experiences of trying to do one's best when the circumstances are such that you'll never feel able to do quite well enough for all sorts of experiences
- Older people feeling indebted as a result of neighbours getting involved
- Neighbours feeling burden and may feel taken advantage of
- Emotional cost of care and how we acknowledge and offer support and resilience and what we do earlier on
- Family care-giving contains a very strong emotional tie

### **Loneliness and depression**

- Older people 'left behind' experience loneliness and depression
- A high incidence of suicide amongst older people in rural China
- Recognising a substantially growing proportion of unbefriended, isolated older adults that don't talk day to day

### **Unpreparedness and uncomfortable discussions**

- It surprises everyone they get old, something they couldn't have foreseen that we are getting older and we've got conditions that are associated with getting older, and this is something people don't talk about and they don't plan for
- Need more open, honest conversations about ageing
- We are an age-denying and death-denying society (UK)
- Preparing for old age is not straightforward as we don't know what it will mean for us as individuals
- Using up resources in short-term means people may not be able to prepare for long-term

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## **Responsibilities for care-giving**

- Relationships amongst individuals receiving care, families, care-providers and the state – where does responsibility sit?
- A strong argument for team-based education of healthcare professions – Lancet Commission

## **Models of care**

- Family care is main mode of elder care in China
- Quality of care in nursing homes in China is not so good and families often prefer to have a nanny or home care-giver
- Grandparents often take on role of taking care of grandchildren in Japan and China
- Are professionals failing in not preparing people for health crises?
- Need to shift focus from 'bad patient' (who doesn't comply or doesn't understand how system works) to focus on 'bad planning' and working to better processes to respond to foreseeable events
- We have to listen to 'the bad patient' as we have a lot to learn from them
- Practices viewed as 'informal' in terms of being a family member and caring for a grandmother
- Role of a palliative care perspective
- Person-centred care doesn't allow us to have a broader understanding of what matters most, relationship-ship centred care enables more meaningful conversations about what matters to the person, what matters to those who are caring for them and what matters to their health and social care providers
- Important role of neighbours and friends in supporting older people
- Always talk of family involvement but there are neighbours that get involved and increasingly that will be the case with so many people are living on their own
- What is the responsibility of neighbours?
- In China, the family play a decisive role in assisting nursing care, including in inpatient care.
- Embrace innovations, for example, a food forum where care home residents cook together
- Importance of paying attention to spiritual needs of care-recipients
- People should be optimally managed at home away from acute care mania
- Attention to transition into hospice end of life care
- What is the role of regulators in supporting ethical care?
- We need to make significant changes to the education and training of health professionals so that they're more aligned to the imperatives of patients' needs than the imperatives of their discipline
- We have to radically flip on its head who has the voice in terms of what needs to be done, needing to be patient-centred. We need to train practitioners to be good listeners

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- We need to design systems that are focused around patient and family and caregiver needs
  - We ought to talk about populations
  - What is the role of chaplains in care processes?
  - We need to mobilise volunteers and community organisations, for example, 'Neighbours Helping Neighbours'

### **Role of technology**

- Enables people to connect with others, for example SMS or internet, and may respond to loneliness and isolation

### **Ethics and care-giving**

- What do we get from caring? And what do we care?
- Social carers who do some of the most complex caring work and are paid less than people who come and clean house. So how does that work out in practice in terms of why do people care? And what do they get from it? And how are they supported?
- Care-givers in China do this as a job, to earn a living, so they may lack care ethics in their practice
- Care-givers in nursing homes often have no education – former Prime Minister of Norway said we needed more hands for elder care but we also need more heads, more brains to do the right work.
- Older people need to be invited to contribute more to their communities
- Missing from the scenarios is the role of professionals, health professionals
- What does it mean to be 'really person-centred'?
- Ethics is really useful because there is often a lot of complexity.
- Not everyone's a natural carer
- The professionalism of care is very palpable in terms of creating a frame where people are expected to but also unhelpful in terms of disenfranchises a lot of care practice
- Role of regulation – do good but also don't penalise them for not being able to do perhaps what's humanly possible
- We need to understand why there's only horror stories (about care)
- We are an ethical business and our values are people who are friendly, reliable, trustworthy and competent – we train people to wipe bottoms but we need to train people about the importance of values within a business. Because the (businesses) with the best values and the best beliefs will deliver the best quality service and its all about quality
- We need to be thoughtful about being able to listen, empathetic listening – professionals taught to talk, not to listen
- We professionalise things that are not professional things. Caring, not care, is critically important.
- The problem with volunteering is that it's unfair, doing what others get paid to do.

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- We talk too much about charity and not enough about justice
  - What is the difference between charity and justice? Charity as doing what people think as right? And justice as doing the right thing
  - What is the role of activism in relation to the practices of care?

### **Cultural differences**

- Much in common across the 4 case studies
- Two cultural differences between the West and the East – traditional Chinese Confucian philosophy underpinning filial piety (respect for elders) and approaches to truth-telling (generally family informed first and not older person)
- Cultural challenges in families, for example, where there is a different dialect and different food
- The Chinese nursing system only trains nurses to carry out doctors' orders and prescriptions and providing some technical nursing care
- What is the relationship between ageing well and character of older adult? Is this restricted to Eastern cultures?

### **PHILOSOPHY**

- **Overarching philosophical questions**
  - Should we take a universal approach to thinking about the philosophy of care for older people
    - The idea of the issues in practical situations raising commonly recognised concerns, regardless of the value system in which you live or commit to as a matter of e.g. religious belief. Note differences here might be very fine-grained (Ireland vs. Northern Ireland; North of England vs South of England)
    - When we do not take a universal approach, we see different roles for philosophy: being encouraged to take up certain roles, not just being permitted to do so
  - Remaining aware of the empirical-normative distinction
    - Just because people do adopt different values in different places, does not mean that they ought to do so. How values play out in the real world is part of the story, but by no means all of it
- **Core values in care-giving**
  - The starting point that every single person has absolute worth and absolute value – everything should flow from this
  - Duties to care
    - A perceived need to respond to vulnerability and address dependency (commonly constructed in the UK) – we respond as individuals to the identified needs of other individuals

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- Practical constraints often constrain the exercise of duty: when there is no family member to care, others (community members etc.) need to recognise that the duty falls upon them
  - Consumerism and duty: people shop around for caregivers often. It has become marketized. The language of inter-personal obligations does not fit well into this discourse
  - Capability theory and the articulation of duties: away from a biomedical or utilitarian framing of the purpose of care towards meaningful opportunities that are fit for translation into person-centred forms of care practice
  - Quality of care
    - Competing norms about what counts as a quality outcome
      - The key question: What is care *for*? What is its *focus*?
      - Set by the older person
      - Automatically involving families and communities as ensuring the outcome results – the integrity of the family, not the individual (present in Chinese philosophical traditions)
    - Ways of realising quality of care
      - Technological and AI interventions, but they come with ethical issues: a risk-benefit calculation and the potential violation of intrinsic ethical values and other dis-benefits (loss of touch, intimacy, authentic non-instrumental care, promotion of inequalities: access limited on wealth/gender lines)
      - Need to be careful of fostering dichotomies here, because the relationship between care and technology can be much more nuanced
  - Equality in care
    - Competing norms about what equality and fairness demand
    - Gendered dimensions of care:
      - In its delivery and receipt
      - In its framing and construction: masculine ideals of independence and choice-focused approaches
      - Possibility of a feminist care recalibration
  - Reciprocity in family care giving relationships
    - Should older people be responsible for caring for their grandchildren? Does this role lead to a requirement for children and grandchildren to care for their older relatives?

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- **Philosophical Blindspots**

- It is fine to talk about overarching values or duties in the abstract, but we must not lose sight of the practical philosophical question of how we properly enact these values or duties in the real world so that people are able to do as they ought to do
  - Not knowing what the value actually requires (e.g. dignity)
  - Practical constraints, e.g. problematic attitudes around discrimination that act against the value being realised (cf. universal human rights frameworks)
- Getting our language right
  - Why are we suddenly presenting as a crisis – something that there is a moral imperative to address – when the challenges we are interested in have been with us for a long time (analogy with climate change here)
  - There is a worry here about our tendency to classify and mis-classify needs (an issue that is present in health care where classifications of disease have closed rather than opened understanding of what people experiencing illnesses actually require and why) – A recalibration of how we understood needs and experiences in old age is required to stimulate the right kind of responses
  - Care constructed as a medical problem and health need to be addressed. There is so much more to care than this
- Epistemic justice
  - Who's voice are we hearing and are we at risk of unjustifiably silencing the knowledge of ageing that older people and those who provide care rightfully ought to be bringing to the table?
  - Cultural dimensions to the performance of this issue: common in East Asia for professionals to talk to family members rather than the older person as a matter of course

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## 9. SUMMARY FINAL SESSION – NOTES RE ‘WHAT WAS LEARNT?’

### Group 1

- What do we think is the most important and the most viable and feasible idea to take forward? How do these ideas relate to understanding the roles and responsibilities in caring for older adults?
- Division of east and west isn't very helpful. The case studies show that cases could have been from east and west. Instead we should move to looking at the principles of care. There should be more philosophy in policy making to give a compass for policy that will be better for patients and care workers.
- There needs to be more of a link between philosophy and policy and practice
- Good model, methodology and approach of this meeting:
  1. Bringing together practitioners, researchers, philosophers,
  2. From different regions and countries to exchange models of practice and learn from each other
- What to do: continue, include more, take project to different regions and places
- The three Ps are very disjointed.
  - How things are and how they ought to be. The journey from is to ought is disjointed. Philosophy in many countries is very noble but in practice the reality often very different.
  - Shows us that systems need to be adjusted so that we can meet the roles and responsibilities.
- Practically we need to document what is actually happening in society, what are the problems and what can we do about it. Test these out and look at cost benefit, so that researchers can have a conversation with policy maker. Have a collective societal request that is built on evidence. We need to understand the barriers to good practice, what are the constraints to people caring in reality, most do want to care but are constrained → **Filial piety** Culture and family are factors that came up strongly, the workshop brought to light that family is not always the answer as families may in some cases do more harm than good.
- Philosophy: points out that we are actually talking more about socioeconomic differences within countries with regard to how well people are cared for, rather than cultural difference such as east west. People who are poor across countries are disadvantaged regardless of which culture they come from.

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- We need to take a broader view, comes down to citizenship and love. We often look at unidirectional care, viewing it as flowing from younger to older but overlook and we devalue older peoples contributions. We need to rethink how we value older people and change perceptions of ageing.
  - Role of gender: maternal grandmothers are the ones who feel a strong responsibility to care for grandchildren
  - Filial piety is a complex phenomenon, so what does it actually mean, what follows and how has it changed over time. Stigma attached to being seen as un-filial, will cause shame but the reality has changed, rural people are often “empty nesters”.
  - Today, socioeconomic situation is what governs the reality of children being less able to look after their older parents, rather than values such as filial piety
    - Old age poverty and fear of being a burden drives older people into suicide in Japan.
    - Ageist societies
    - Governments often invoke notion of filial piety to rid themselves of their responsibilities to support families, some countries on Asia even have policies which punish families who do not look after their older people
  - Under-appreciation of the diversity of older populations. We need to understand the diversity before we make policies, as current negative views of ageing casts older people as underproductive and their real contributions to their families such as through family caregiving are often under-recognised.
  - Ageing needs to receive more positive recognition (its not only about illness and suffering) without overlooking that many older people will need care and support.
  - We speak a lot about children left behind but not about older people left behind. Children left behind get much attention in public policy and statistics because children will be the work force of the future. Need to pay more attention to older peoples worth and value that is beyond economic and productivity terms.
  - Diversity within families, who should take what role, will also depend on what each family member is equipped to do.
  - Work ethic: we often think of this as working hard, rather than look at the ethics we bring to our work
  - Filial piety: Original meaning of this term was that the junior males would need to look after senior males in the families

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## NEXT STEPS?

- We should continue but not repeat the same thing but take it a step further.
- Start a research project between our countries, breaking up into 1-2 specific research subjects
- Further networking – like this or should other parties be invited, bring in more politicians to make it more translational
  
- Write up from the proceedings of this meeting so we capture what we have learnt
- Start with each country and look at the demographics, health, social and psychological situation within each country
- Within each country have consultations to see if there are synergies between what we have discussed here at the meeting with our respective countries
  
- Get together across occupations and countries
- We should find a way to continue this
- **Link in with existing activities and conferences in the respective countries**
- Health and humanities taskforce
  
- Getting more specific in the future, clustering around **countries income groups** or other parameters as socio-economic and policies differ very much between countries and this impacts care on the ground
- Including lower-income countries more strongly in this agenda
  
- Pick up a specific topic, for example elderly suicide comparative study across countries
  
- Important to record and capture discussions from the workshop, share commentaries, or write a paper together
- Cluster countries by income groups? or income groups within countries – probably find more similarities between low income older people across countries than high income and low income older people within a single country.
- Socioeconomic status of older people
  
- **Keep an eye on outcomes – what do we anticipate, how can we operationalize the learning to actually improve the lives of older people**
- Do we want to influence policy or are we pursuing other goals?
- Challenge some of the assumptions about ageing using a peer lead course, similar to “action for happiness” in the UK. This could then be translated into other settings (e.g. model on death and dying, stigma)
- Making academic work practically accessible and translating it into something that is practical

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- Report and proceedings of conference needed
  - Translate knowledge into more practical actions as well as recommendations to policy makers
  - **What is our goal? What does a healthy (physical social psychological and spiritual health) in older age look like? And then using this as a goal to work towards**
  - **UNESCO MOST - models of social transformation:** Ageing well 6-8 speakers, 50 scholars meet 4-5 days for workshops, field visits, trainings; at the end report is produced and scholars then become ambassadors in their countries

## Group 2

- Important to record and capture discussions from the workshop, share commentaries
- We should continue but not repeat the same thing but take it a step further.
- **Getting more specific going forward:** there were various suggestions on how to do this:
- **Within each country have consultations** to see if there are synergies between what we have discussed here at the meeting with our respective countries
  - Start with each country and look at the demographics, health, social and psychological situation within each country
- **Link in with existing activities and conferences in the respective countries**
- **By countries/ or regions?**
  - Cluster countries by income groups? or income groups within countries – probably find more similarities between low income older people across countries than high income AND QUESTION ABOUT low income older people within a single country?
- **Keep an eye on outcomes:** *how can we operationalize the learning to actually improve the lives of older people*
  - **What do we want to achieve?**
  - **Who do we want to influence?**
- Do we want to influence policy or practice or are we pursuing other goals
  - Making academic work practically accessible and translating it into something that is practical

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- **Influencing academia:** Pick up a specific topic: Writing papers, special issue eg on filial piety AND elderly suicide comparative study across countries
  - **Policy:** MOOC, MOST, peer lead course Challenge some of the assumptions about ageing
  - Further networking – like this or should other parties be invited, bring in more politicians to make it more translational

## **10. Concluding Remarks on the Chinese Context from Professor Yonghui Ma**

'The two Chinese cases originally come from Prof. Xu (home care case) and Prof. Fang (residential care case), i did some of the translating and editing work. The original figure in the home care case, the 94-year-old Mr Wu, is actually Prof. Xu 's father. When the case was completed after many rounds of changes, I heard from Prof. Xu that his father has passed away. I understand how hard for Prof. Xu to go through the details of looking after his father when the person has just passed away, I just wanted to say thank you for Prof. Xu and Prof. Fang for your hard work.

Whose responsibility? What do we owe to elder members in our society? how to care for elderly? What care should we provide? How the eldercare policy fit in the general social policy? These are the questions to need to address before a successive, responsible, and humane eldercare policy can be developed. From today's discussions, we have identified many challenges and difficulties, which could come from social systems, public policies, economic infrastructures, also related to different society phases, culture characterization, and ethical considerations. For the case of China, it faces some special problems I have identified some of them:

Firstly, the rapid economic development cannot cope with the even faster pace of getting old before getting rich. China entered into aging society since 1999, so 20 years. But there is still huge disparity in terms of the average income per capita between China and developed countries. On 1999, the income per capita is only 865 dollars (ranking 112), 2017 the number is 8582 dollars, ranked 74<sup>th</sup> globally. We can see that the economic development cannot satisfy the rapid aging need.

Secondly, in terms of social structure, there is the urban-rural dual structure model for eldercare. In the coming October, china will be celebrating its 70 years anniversary of establishment and 40 years anniversary of "economic reform and open-door policy". There are serious challenges of uneven and unbalanced development, especially the urban-rural dual structure. For older people who live in urban cities and have good pensions, they have much better access to resources and family care. For those elderly who left behind live in rural and deprived areas, their sons and daughters working in bigger cities, these people have very limited access to healthcare resources. There has been lack of adequate prediction and attention to the problem of aging and the modern transformation of how elder care is conceived lags behind the aging development.

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Thirdly, in terms of population policy, the one child policy has strictly implemented more than 30 years and it has led to eldercare crisis. For many Chinese families, there are 4-2-1 model, 4 grandparents, 2 young parents, and 1 child. There is huge pressure for young people to take care of parents and grandparents.

Fourthly and lastly, in terms of tradition and culture, china has a tradition called “bring up sons to support parents in their old age”, this belief is deeply embedded. In Confucianism, family/home is not only a sociological construct, having political significance, but also has moral symbols and cultural values, caring special moral obligations. The meaning of Filial piety is not reflected in the respect for elderly, but also embodies the duty of caring for older parents. Even in the social transition period, although there are community eldercare, institutional eldercare, these forms of caregiving cannot totally replace the expectation and value of family care. Therefore, there are problems of how to combine different forms of care.

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## 11. CONCLUSION & NEXT STEPS

The report concludes with an overview of the subsequent work that Ann Gallagher and Mikey Dunn are planning to take the project further. Invitations will be extended to project partners to participate in the preparation of papers, case studies, and further grant applications as appropriate. Further details about these opportunities will follow in due course. **Your advice is also sought on future research grant application plans - please see below:**

1. Provisional plans for publishing case studies
  - One on each P?
  - Practice – practice-based journal
  - Philosophy – think about what the angle would be
  - Education development paper – case study and commentaries in learning
  
3. Plans for a new research programme - Collaborative award grant?
  - What works and doesn't work?
  - How ought the collaboration function (beyond a mere collection of separate projects?)
  - What outputs are appropriate for this kind of grant?
  - Engagement events – at Wellcome Collection?
  - Rationale: challenging perceived wisdom? Demolishing stereotypes, and essentialist and romanticised accounts of care?
  - International hub-based approach? North America / East Asia / South-east Asia / Africa?
  - Mutual learning – across sites? Replication?
  - Differentiated models of care (family / technology / migration-based / voluntary?)
  - Organisational case studies?
  - Cross-cutting themes (gender / class / culture-religion / wealth / ethnicity?)
  - Different philosophical perspectives (African (Caesar Atuire) / Confucian / Care ethics / Reciprocity / Solidarity)
  - Responsibilities of older people? What are the questions going to be?
  - Empirical and normative analytic work?
  - 3 Ps & Roles and responsibilities (professional and non-professional) – should these remain a central focus of further analysis in a larger programme of work?
  - What are the perspectives of different generations? For example, Generation Z (young people); Baby Boomers (people in their middle years); and the Silent Generation (older people born 1945 and before) – regarding the meaning, implications and promoters of 'healthy ageing'?

We have very much enjoyed working with you on this project look forward to your advice regarding next steps. **Ann Gallagher & Mikey Dunn 30<sup>th</sup> September 2019**